DOCUMENT RESUME

ED 335 853 EC 300 595

AUTHOR Lutfiyya, Zana Marie
TITLE Personal Relationships and Social Networks: Facilitating the Participation of Individuals with Disabilities in Community Life.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
PUB DATE Apr 91
NOTE 99p.; For a related document, see ED 307 738.
PUB TYPE Collected Works - General (020)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS *Citizen Participation; *Developmental Disabilities; *Friendship; *Helping Relationship; Interpersonal Relationship; Quality of Life; Severe Disabilities; *Social Integration

ABSTRACT

This monograph presents four papers which focus on the experiences of people with disabilities in terms of their personal relationships and belonging to a social network. The first three papers are authored by Zana Marie Lutfiyya. An overview article, "Reflections on Relationships between People with and without Disabilities," describes some of the factors that influence the possibility of such relationships. Noted are the lack of opportunities of many developmentally disabled persons to meet others in ways conducive to developing personal relationships. The second article, "Affectionate Bonds: What We Can Learn by Listening to Friends," was excerpted from a larger monograph. This article describes conclusions drawn from observing four such integrated friendship pairs. The third article, "Tony Santi and the Bakery: The Roles of Facilitation, Accommodation, and Interpretation," describes one disabled man's social network and the efforts of others to ensure his continued involvement and participation. The fourth article is by John O'Brien and Connie Lyle O'Brien and is titled, "Members of Each Other: Perspectives on Social Support for People with Severe Disabilities." It examines the meaning of membership in a community and ways that such membership can be established for individuals with severe disabilities. An annotated bibliography provides abstracts of 23 publications also addressing these issues. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED335853

PERSONAL RELATIONSHIPS AND SOCIAL NETWORKS: FACILITATING THE PARTICIPATION OF INDIVIDUALS WITH DISABILITIES IN COMMUNITY LIFE

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality

- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

APRIL 1991

Prepared by:
Zana Marie Lutfiyya
The Center on Human Policy
School of Education
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

CONTENTS:

PART I: OVERVIEW ARTICLE: REFLECTIONS ON RELATIONSHIPS BETWEEN PEOPLE WITH AND WITHOUT DISABILITIES
by Zana Marie Lutfiyya

AFFECTIONATE BONDS: WHAT WE CAN LEARN BY LISTENING TO FRIENDS
by Zana Marie Lutfiyya

TONY SANTI AND THE BAKERY: THE ROLES OF FACILITATION, ACCOMMODATION, AND INTERPRETATION
by Zana Marie Lutfiyya

MEMBERS OF EACH OTHER: PERSPECTIVES ON SOCIAL SUPPORT FOR PEOPLE WITH SEVERE DISABILITIES
by John O'Brien and Connie Lyle O'Brien (to be published in J. Nisbet (Ed.), Natural supports. Baltimore: Paul H. Brookes Publishing Co.)

PART II: ANNOTATED BIBLIOGRAPHY OF RELATED READINGS
by Bonnie Shoultz, Zana Marie Lutfiyya, and Susan O'Connor

EC 300595

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
S. Taylor

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

BEST COPY AVAILABLE

PREFACE

This packet (originally published in 1988 as "Materials on Relationships") was revised in response to continued requests for information on how to develop and support a variety of personal relationships between people with and without disabilities. This area has been receiving a lot of attention, and a variety of programmatic efforts to build bridges between individuals who are clients in the human service world and nondisabled citizens are underway across the country.

Part I consists of four articles which focus on the experiences of people with disabilities in terms of their personal relationships and belonging to a social network. Researchers at the Center on Human Policy are finding that many individuals with disabilities do not belong to extensive networks of people with whom they share affection and support. Many of the individuals suggested to us as being well connected have in fact, only one, two or three friends. The primary source of possible connections for many individuals with developmental disabilities remain their families, staff and the other people who are in the same programs and services.

The overview article, "Reflections on Relationships Between People With and Without Disabilities" (first published in 1988), describes some of the factors that influence the possibility of relationships between people with and without developmental disabilities. Largely due to their experiences in the human service system, individuals with disabilities often have fewer opportunities to meet others in ways conducive to the formation of friendships and other personal relationships.

The second article, "Affectionate Bonds: What We Can Learn by Listening to Friends," was excerpted from a larger monograph[1], and published in the TASH newsletter (January 1990). This article describes the meanings of four pairs of friends Within these personal relationships between individuals with and without disabilities, the nondisabled people have facilitated the involvement of their friends into a number of activities with others.

The third article, "Tony Santi and the Bakery: The Roles of Facilitation, Accommodation, and Interpretation," describes one man's social network, and the efforts of some individuals to insure his continued involvement and participation.

---

[1] The annotated bibliography section contains a description of this monograph.

The fourth article, "Members of Each Other: Perspectives on Social Support for People with Severe Disabilities," examines the meaning of membership in a community, and ways that such membership can be established for individuals with severe disabilities.

In Part II, an annotated bibliography on personal relationships and social networks in included.

Preparation of this packet was supported in part through a subcontract to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, from the Research and Training Center on Community Living at the University of Minnesota under Cooperative Agreement No. H133B80048, and a contract awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University under Cooperative Agreement H133B00003-90, both funded by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. The opinions expressed herein are solely those of the authors and no official endorsement by the U.S. Department of Education should be inferred.

I'd like to thank Rachael Zubal and Bonnie Shoultz for their encouragement and assistance in preparing this packet.

Zana Marie Lutfiyya
April 1991

Reflections on Relationships Between People with Disabilities and Typical People

Zana Marie Lutfiyya
Center on Human Policy
Syracuse University
August 1988

The author thanks Bonnie Shoultz, Rannveig Traustadottir, Steve Taylor, Pam Walker, and Julie Ann Racino for their assistance during the preparation of this article.

Reflections on Relationships Between People with Disabilities and Typical People

> "Basically we should look at how we live--the different relationships we have, the choices we make, and so on--and aim to ensure that our friends with handicaps have the same sort of fulfilling lives we have.
>
> \- Nicola Schaefer

Common Experiences of People with Disabilities

It seems trite to assert that people with disabilities possess the desire and need for relationships with other human beings. Don't we all? Yet at a recent training session with the staff from a residential program, the lack of relationships in the lives of people with disabilities was clearly pointed out. Thinking of the people they worked with, the staff determined that none had "best friends." A few of the residents could claim one or two "close friends" while two enjoyed warm ties with their families. All of the residents knew half a dozen or so "acquaintances" with whom they maintained casual contact. The majority of the people the residents knew were staff, other residents, and the people with whom they conducted the daily business of their lives; doctors, dentists, shopkeepers, and so on.

Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in their community. Surrounded by paid staff and others receiving the same services, people with disabilities are made into "clients," "service users," or "program participants." Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Such occurrences are not infrequent. They take place so often that they form a pattern--the "normal" existence for people with disabilities.

It doesn't have to be this way. Some people with disabilities are well-loved, treated with respect and encouraged to remain connected with their families, typical peers, and people they have known in the past. However, it is important to recognize some of the other dynamics that exist in the lives of people with disabilities.

"Us and Them": Being Seen as Different

The heart of this matter lies in how most non-disabled people view their counterparts with disabilities. Over time our society defined people with disabilities as somehow different than the rest of us, and in need of specialized care. The view that individuals with disabilities are in some ways essentially different from the rest of us results in several types of experiences. People with disabilities are separated from their families and communities, cast into roles of dependency and passivity, and even when physically present in some community settings, are kept at a social distance from the other members of the community.

Separation

The pattern of the historical removal of people with disabilities from our society is well-documented. Large numbers of individuals were placed into large congregate-care facilities for the avowed purposes of education and training, medical care, family relief or social control of unwanted segments of the population (MacMillan, 1977; Scheerenberger, 1983; Wolfensberger, 1977). Some concentrated efforts were also made to sterilize certain groups to prevent their propagation and also to kill them outright (Lusthaus, 1985; Wertham, 1973).

The enforced segregation of people with disabilities from the daily life of their communities reinforced the belief that some people are so different that they cannot fit in or successfully contribute to their society. Typical community members lose the chance to meet, get to know, and be with individuals with disabilities. The opportunities for people in both groups to grow up together, and form attachments with each other are often lost.

Clienthood

By entering a program, most people with disabilities are turned into "clients." During this process, a person is cast into a dependent and passive relationship with the staff and other caregivers. When the client role becomes life-defining, the person can become lost and emphasis is placed on the person's deficits. Teachers, doctors, therapists and other workers are hired to correct the problems seen as inherent in the disabled person.

As a "client," a person learns to show the acceptable behaviours at the right times in order to get by. Consider the following incident. The author recently met two young women who shared an apartment and received support from visiting staff people. The women set up menus, bought food, and cooked the meals, all with the staff's onlooking approval. Once left to their suppers, the women would throw out these meals and prepare the food that they wanted to eat.

Given the above dynamics, it is not surprising that there is little mutual respect found in many relationships between program staff and clients. As part of their jobs, the staff attempt to control the lives of their clients, who in turn try to maintain some control over their own lives. While the staff may define the client's behaviour as manipulative, self-destructive and so on, they in turn may view that staff as capricious, inconsistent or simply out to get them (Bogdan & Taylor, 1982; Lovett, 1985).

A common part of any client's life that is under the control of staff people are the individual's contacts and relationships with others. Both children and adults with disabilities may be restricted from visiting their families or friends, from developing relationships with others.

Being a client can create barriers in the development of reciprocal and nourishing relationships with others. Through rare or a complete lack of opportunities, people with disabilities become slowly desperate for connections with others that are not governed by control (McGee, Menousek, & Hobbs, 1987). As virtually all people served by human services agencies are "clients," the area of relationships between people with disabilities and typical citizens needs to be addressed.

The People In Our Lives

Most of us take the notion that humans are social beings for granted and are surprised to learn that others may not have the same range of friends, family, and acquaintances as we do. Most of us would agree that there are degrees of closeness or intimacy across our own relationships. We acknowledge intimates or "best friends" as those few people who are closest to ourselves--at least in terms of understanding and support. They are the ones we can turn to, in any situation. Next come our friends, and then acquaintances--friends of friends, people who are not strangers. We "know" this latter group, but not well. Finally are the numerous people whom we see regularly, but for specific purposes; the postman, doctor, shopkeeper and so on.

Developing and Maintaining Relationships

Helping someone to meet people and make friends can be difficult. Formal, programmatic efforts to do so contradict our society's notion of how relationships are formed. We do not think of ourselves as reliant upon arranged marriages, strict kinship obligations, or planned introductions between people who might be "good for one another." The possible exception to the latter case are potential business associates, where purely utilitarian needs are considered appropriate.

Arranged introductions seem an artificial and heavy-handed way to establish relationships. And yet, some human service providers are attempting to do just this in order to surround people with disabilities with a number of friends and close ties. These efforts are made in order to overcome the barriers that prevent more naturally occurring relationships from taking place. Despite the obstacles, it cannot be denied that warm, reciprocal relationships between typical people and those with disabilities exist (Bogdan & Taylor, 1987b; Strully & Strully, 1985; Taylor & Bogdan, 1987). Along with the growing recognition of the importance of such relationships are human service staff hired to "build-bridges" between people with disabilities and typical people (Bogdan, 1987; Johnson, 1985; Walker & Salon, 1987).

Both popular wisdom and the literature on this subject suggest several factors that may be involved in the development and maintenance of relationships. What is still not resolved is precisely how these factors are related to each other and their impact upon individuals.

Some Qualities and Dimensions of our Relationships

It appears that at least six characteristics experienced by typical people in their efforts to meet others and develop relationships may not be as available for people with disabilities. These qualities of our relationships include opportunity, diversity, continuity, relationships that are freely chosen and given, and intimacy.

Opportunity

Typical people can take advantage of numerous opportunities to meet and get to know other people. We meet others through our families, neighbours, school/workplace, cultural, civic, and recreational events, church, synagogue. We also come into contact with innumerable individuals simply in conducting our daily affairs--buying food, getting the car fixed, taking care of our health needs, hair cut, mail received or sent. In our western culture, it requires effort to avoid meeting new people.

For many people with disabilities, such opportunities are simply lacking, and they possess extremely limited opportunities to take part in activities and events where they can meet their typical peers. We read of adults who did not know what rain was (Rothman & Rothman, 1985), or a woman who had never sat by a lighted fireplace (Bogdan & Taylor, 1982). And even when people with disabilities may be physically present in a community, a variety of circumstances conspire to keep them apart from their neighbors (for example, program rules and restrictions, transportation, poverty).

Support

Providing adequate opportunities for people with disabilities to meet and interact with valued citizens in positive ways must be the first step towards the building of meaningful relationships. Hand in hand with these opportunities must be adequate support for both the person with disabilities and the typical people involved. One woman wanted to go to church, as she had not attended since she was a child. A church of the right denomination was located, the priest contacted, and a parishioner agreed to sit with Helen during Mass and accompany her to the coffee hour afterwards. For Helen, this effort was not enough. She did not know how to behave in church, and smoked cigarettes, talked, and swore during the service. Not surprisingly, the parishioner became uncomfortable sitting next to Helen, and soon stopped coming to pick her up. Helen needed someone comfortable enough to direct her actions quietly while in church--suggest going out for a smoke, or waiting, being quiet. Initially, a staff person sensitive to Helen's need to attend church and to the limits of appropriate behaviours might have made the difference, by minimizing disruptions, allowing Helen to attend church and meet others in the congregation. This staff person could then encourage a member of the congregation to support Helen, in the hope that a friendship would develop. Enhancing relationships between people with disabilities and typical citizens is not accomplished by throwing unprepared and unsupported individuals together.

On the other hand, support, instruction, and guidance must never be confused with restricting a person's opportunities to meet and form ties with other people.

Human service programs have historically controlled and limited the opportunities available to individuals with disabilities.

Diversity

At a party once, one man suggested that even with only ten people in the room, one of us would know someone who came from, or have been ourselves, to virtually any country in the world. The first skeptic named Borneo only to learn that one woman's Malaysian secretary was born on the Island of Borneo. A coincidence perhaps, but if we stop to think about it, we know an incredibly diverse range of people with differing backgrounds, interests, jobs, education etc. Although we may not choose to associate with, or become close to everyone we meet, we have the opportunity to select our friends from a large number of very different people.

Unfortunately, the same cannot be said of many people with disabilities, especially those who were raised apart from their families and neighbourhoods. People served in both institutional and community-based settings may experience little contact with people other than fellow clients and staff people. Along with increased opportunities for people with disabilities to meet typical citizens must come the support to get to know a variety of individuals.

As we introduce people with disabilities to more people, we must also give up some of our control over their lives. The excessive control that human service staff now exercise over their clients would be socially inappropriate in the types of relationships that we wish to encourage. We must constantly discern the line between adequate support, guidance and protection and the over-protection that unnecessarily restricts a person in his/her movements and associations.

Continuity

Many of us thrive on opportunities to meet new and interesting people. But as we continue to meet new people, we are sustained by those we have known for a long time. The continuity we experience in some of our relationships over the years is an important source of security, comfort and self-worth. Human beings learn to trust each other within long-term, stable relationships (Maslow, 1954; McGee, Menousek, & Hobbs, 1987).

Many people with disabilities do not enjoy the same continuity in their relationships. Children may leave their families for foster care or residential education programs. Staff people, social workers and case managers can come and go frequently, causing disruption in a person's life. Wolfensberger (personal communication, mid 1970s) likens many people's experiences to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding instantaneous trust from the person with disabilities. An observer in a supported apartment program learned that her five months observation gave her some seniority over most of the support staff (Lutfiyya, 1987).

The service providers who surround people with disabilities must learn to support and not to stand in the way of long-standing relationships of the people they serve. Assisting people to stay in touch is essential. Letters may need to be written and read, phone numbers dialed, transportation provided. Helping a person to remember birthdays, anniversaries and other important occasions are ways to maintain ties. Some people may need help to remember and cherish the history of their connections with others. Some individuals may need assistance during a visit or social event with a friend or relative; such as how to be a gracious host (or guest), how to carry on a conversation, or observe other social graces.

Freely Given and Chosen Relationships

For the most amazing reasons, others like us and love us because they want to. Our spouses, lovers, and friends all choose to be with us and we choose them. We are surrounded by people who accept, love and tolerate us and we do the same for them. When this is not the case, we think that something must be wrong somewhere, and seek to rectify the situation. Popular culture and our books of wisdom assert that this is as it should be.

Many people with disabilities enjoy few close relationships with others, and even fewer unpaid relationships (Johnson, 1985). The main source of relationships for a lot of people with disabilities are their families, program staff and other clients. Given the lack of opportunity and support to meet people in the community this should not surprise us. Yet it can be difficult to appreciate what life is like for people who know no single person who spends time with them because they want to, not because they are paid to do so or are involuntarily placed in the same setting.

Too many human service program practices prevent freely-given relationships from developing. This includes practices such as requiring someone to become an official agency volunteer, attending a training course before meeting the clients, restricting visiting times and placing the typical people in positions of control. When freely given relationships do occur, human service agencies often deny the importance of the relationship. One young woman met a three year old girl living in a children's rehabilitation hospital. Abandoned at birth, Rose lived with several debilitating physical conditions making some movement and handling painful. The woman visited Rose, read her stories, sang songs, rocked her to sleep. One week when Judy came to visit, she found another child in Rose's bed. Rose had died a few days earlier. When Judy, the woman questioned why she had not been contacted, and why no memorial service was planned, she was offered grief counselling. The staff also expressed surprise over Judy's attachment to Rose.

All of this is not to deny that some paid relationships are characterized by genuine warmth, caring and even love. But it is essential to recognize this quality in our relationships and its absence from the lives of many people with disabilities. Our goal must not simply be to introduce people to others, but to create the environment that will encourage typical members of our communities to voluntarily choose to form relationships with people whose lives have been marked by separation and loss. Human service staff hoping to support friendships between people with disabilities and typical community members can be direct in their efforts. They can ask themselves, "who seems to be interested in this person?"; "who likes this person?" and "who wants to spend time with this person?"

Intimacy

With its many meanings, the word intimacy may be confusing. It is used here as an expression of the closeness, comfort and trust that people may feel for each other. Intimates can express thoughts and feelings that they share with no one else. Despite the difficulties in determining how a person defines those s/he is "closest to", most people have (or aspire to) a few "intimates."

We are just beginning to recognize that many disabled individuals have no one with whom they share a close, intimate relationship. Some may claim such a connection with another, and find this closeness is not shared by the other person. It would be easy to interpret this "fantasy" as a result of the person's cognitive impairments. But if at least one intimate connection with another human being is vital for each of us, this "fantasy" may be necessary for the individual's functioning. There is no easy answer for those who want to support intimate relationships between people with disabilities and their typical peers. All humans struggle in their search for intimate connections with other people.

Learning from the Relationships of Others

Two themes emerge from a reading of the available literature on the development and maintenance of relationships between typical and disabled people. Often those engaged in the relationships do not see their involvement as unusual or worthy of note. They almost take the relationship for granted (Bogdan & Taylor, 1987b). Secondly, the reduction of barriers and the increase in identification between the two potential friends appears important in creating a mutually respectful relationship (O'Brien, 1987).

The Possibility of Relationships

It is important not to deny the history of any individual or of a group of people. We must never forget the generations of abuse and neglect visited upon people with disabilities, nor lose sight of the tragic pasts (and present circumstances) of the individuals with whom we work today. But we must also believe that a variety of accepting relationships between typical and disabled individuals are possible (McKnight, 1987). We must provide opportunities where people can comfortably come together to meet each other, and we must learn to recognize when we are standing in their way.

Increasing Identification

Through studying established relationships, we learn that both parties possess a mutual respect for the other. Partners also report a reciprocity in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship.

Bogdan & Taylor (1987b) suggest several bases of identification held by the non-disabled person that might account for their acceptance of people with disabilities. These include family ties, religious or humanitarian beliefs.

People involved in Citizen Advocacy (O'Brien, 1987; Wolfensberger & Zauha, 1973) attempt to create and support a variety of relationships between disabled and non-disabled individuals who live in the same community. They pay close attention to the process of increasing the identification of the two people with each other, especially when the commonalities may not be obvious.

Conclusion

A mark of real acceptance of individuals with disabilities in our communities can be found in the real relationships they enjoy with typical people. It is probably not possible to create such relationships despite the efforts of people in the human services to do so. However, the opportunities for disabled and non-disabled people to meet and interact can be increased and encouraged. The dilemma for human service workers is the recognition that their programmatic presence may in fact serve as a barrier to the development of the desired relationships.

References

Bogdan, R., & Taylor, S. J. (1982). Inside out: The social meaning of mental retardation. Toronto: University of Toronto Press.

Bogdan, R. & Taylor, S. J. (1987a). Conclusion: The next wave. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 209-213). New York, NY: Teachers College Press.

Bogdan, R. & Taylor, S. J. (1987b). Toward a sociology of acceptance: The other side of the study of deviance. Social Policy, Fall 1987, 34-39.

Boles, S. M., Horner, R. H., Newton, J. S., & Romer, L. (1985). The neighborhood living project: A community residential model for citizens with severe handicaps. Eugene, OR: Specialized Training Project, University of Oregon.

Forest, M., & Snow, J. (1983). The Joshua committee: An advocacy model. Leisurability, 10(1).

Johnson, T. (1985). Belonging to the community. Madison, WI: Options in Community Living and Wisconsin Council on Developmental Disabilities.

Johnson, T., & O'Brien, J. (1987). Carrying Options' story forward. Madison, WI: Options in Community Living.

Lovett, H. (1985). Cognitive counseling and persons with special needs: Adaptive approaches to the social context. New York, NY: Praeger.

Lusthaus, E. (1985). "Euthanasia" of persons with severe handicaps: Refuting the rationalizations. Journal of The Association for Persons with Severe Handicaps, 10(2).

Lutfiyya, Z. M. (1987). [Unpublished field notes]. Syracuse, NY: Author.

MacMillan, D. L. (1982). The mentally retarded in school and society. Boston, MA: Little, Brown & Company. (1st published in 1977).

Maslow, A. (1954). Motivation and personality (1st ed.). New York, NY: Harper.

McGee, J. J., Menousek, P. E. & Hobbs, D. (1984). Gentle teaching: An alternative to punishment for people with challenging behaviors. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities. New York, NY: Teachers College Press.

O'Brien, J. (1987a). A guide to lifestyle planning. In B. Wilcox & G. T. Bellamy (Eds.), A comprehensive guide to the activities catalog. Baltimore, MD: Paul H. Brookes.

O'Brien, J. (1987b). Learning from citizen advocacy programs. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1986). Strengthening the system. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1987). Framework for accomplishment. Atlanta, GA: Responsive Systems Associates.

Perske, R. (1980). New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better. Nashville, TN: Abingdon Press.

Perske, R. (1988). Friends circle to save a life. TASH Newsletter, 14(1).

Rothman, D. J., & Rothman, S. M. (1984). The Willowbrook wars. New York, NY: Harper & Row.

Schaefer, N. (1978). Does she know she's there? Toronto: Fitzhenry Whiteside.

Scheerenberger, R. C. (1983). A history of mental retardation. Baltimore: Paul H. Brookes.

Strully, J., & Strully, C. (1985). Friendship and our children. Journal of The Association for Persons with Severe Handicaps, 10(4).

Taylor, S. J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance. Disability, Handicap & Society, 4(1), 21-36.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Taylor, S. J., Biklen, D., & Knoll, J. (Eds.). (1987). Community integration for people with severe disabilities. New York, NY: Teachers College Press.

Walker, P., & Salon, R. (1987). Supporting people in the community: A case study of the residential support program--Centennial Developmental Services, Weld County, Colorado. Syracuse, NY: Center on Human Policy, Syracuse University.

Wertham, F. (1973). The German euthanasia program. Cincinnati, OH: Harps Publishing.

Wolfensberger, W. (1973). Program analysis of service systems, PASS (3rd ed.). Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1977). The origin and nature of our institutional models. Syracuse, NY: Human Policy Press.

Wolfensberger, W., & Thomas, S. (1983). Program analysis of service systems' implementation of normalization goals. Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Zauha, H. (Eds.). (1973). Citizen advocacy and protective services for the impaired and handicapped. Toronto: National Institute on Mental Retardation.

Affectionate bonds: What we can learn ...by listening to friends

by Zana Marie Lutfiyya

*This article contributes to the continuing dialogue about friendships between people with and without disabilities. Those interested in a monograph on this study should contact **Zana Marie Lutfiyya**, Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-4230.*

Many people in the fields of special education and rehabilitation today have a strong desire to help people with developmental disabilities develop a wide variety of personal relationships, including friendships, with people without disabilities. It is becoming widely acknowledged that such relationships enrich the lives of both the persons with disabilities as well as those without and better enable persons with disabilities to become more a part of the community. Some human service providers are now trying to create opportunities for people with developmental disabilities to meet and develop friendships with people without.

Some of these efforts have evolved into formal programs, despite the fact that, for many of us, arranged introductions are an artificial and heavy-handed way of establishing friendships.

Our good intentions aside, we still know little about the nature and meaning of "naturally occurring" friendships that do exist between people with disabilities and those without. There are about a dozen case studies and/or testimonials available which describe either the authors' friendships with persons with disabilities (Edwards & Dawson, 1983; Forest & Snow, 1983) or the authors' observations of the friendships of others (Perske, 1988; Strully & Strully, 1985a, 1985b; Strully & Bartholomew-Lorimer, 1988).

I wanted to learn more about these naturally occurring friendships between individuals with developmental disabilities and those without. So, I spent time with four pairs of friends to learn how they had first met, developed and maintained their friendships and what those friendships meant to each of them. I conducted indepth and open-ended interviews and participant observation sessions with the four pairs of friends. Each pair consisted of one person with a developmental disability and one without. Both people in each of the pairs identified themselves as friends. My intent was that the stories, words and perspectives of the people I interviewed would contribute to our understanding of how affectionate bonds which exist between people are created and maintained.

From my analysis of the data, five major findings emerged. First, genuine friendships between people with developmental disabilities and people without *do exist*. Second, each of the informants took active parts in the creation of their friendships. Third, the informants played different roles vis a vis their friends. Fourth, while the specifics of each friendship were unique, the informants shared similar ideas and expectations about the characteristics of friendship in general. These included the mutual, exclusive and voluntary nature of friendship; the rights, obligations and responsibilities of friends to each other and the positive regard or affection found between friends. Fifth and finally, the fact that one of the friends in each pair did have a developmental disability did play a role in the friendships. While both of the friends contributed something to the friendship, the kinds of contributions made did depend on whether or not the respective friend had a disability.

Genuine friendships

The people with developmental disabilities were in fact considered friends by the informants without disabilities. Through these and other similar relationships reported upon in recent literature (Bogdan & Taylor, 1987; Edgerton, 1988; Forest & Snow, 1983; Perske, 1988; Strully & Bartholomew-Lorimer, 1988; Strully & Strully, 1985; Taylor & Bogdan, 1987), the existence of friendships between people with disabilities and without has been documented. The people with developmental disabilities in this study enjoyed very few personal relationships and even fewer friendships (regardless of whether their friends had developmental disabilities). Although friendships among people with and without disabilities still appear to be the exception rather than the rule, some individuals with developmental disabilities are valued as friends. They are liked, loved, appreciated and viewed with respect by their friends who have no disabilities.

Joint definition of friendship

The second finding of this study related to how the friendships were formed. In three out of the four friendships studied, it was the person with disabilities who initiated the friendship. The friends actively created their friendships. The result is that they came to define their relationships with each other as friendships.

BEST COPY AVAILABLE

Friends play different roles

The data clearly illustrated that the friends played different roles (e.g. mentor, companion, advocate) within their friendships. One of the friendships was between two co-workers and revolved largely around work-related activities and events. One of the friendships was intense and intimate, while in the others, the friends assumed a more casual relationship with one another. One friendship was focused on a particular interest and was limited to certain activities, while the other friendships existed regardless of what activities the two friends were involved in while together. Some of the friends had frequent, perhaps daily, contact, while others saw each other far less often. Two people maintained a friendship by telephone and had very little direct face-to-face contact.

Friendships are meaningful

Each friendship was meaningful for the informants. These meanings were similar across all four friendships. For the informants, their friendships were mutual relationships which involved certain rights and responsibilities on the part of each of the friends. They acknowledged that their friendships were voluntary and their obligations chosen. While in each group, both of the friends contributed something to the relationship, these contributions differed according to whether the friend had a disability. Once a friendship bond was established, it was most often the person with the disability who made the phone calls, suggested possible activities and events and were most likely to remember holidays, anniversaries and so forth. On the other hand, it was the persons without disabilities who provided the transportation, occasionally contributed money for activities, took care of any logistical arrangements and facilitated interactions between their friends with disabilities and others.

The relationships were generally exclusive, e.g., to a certain extent the people involved excluded others from their respective friendships. Through the process of defining and maintaining a friendship over time, each of the informants had learned how to be a friend. This was not the first or only time that any had been engaged in a friendship. But by being seen as—and seeing themselves as—friends, and being treated as friends, each of the informants was able to assume the friendship role and learn something about being a friend. In this way, they were able to take part in the practice of friendship.

Implications of the study

Three themes evolved from the study and provide a basis for drawing some conclusions: The effects of living in the human service world, the enhancement of possibilities for friendship between people with and without disabilities and the avoidence of the romanticization of these friendships.

1. Living in the human service world

First, the majority of people the informants with disabilities knew were staff and other people with disabilities. While three had had contact with their families over the years, the majority of people in their lives were those with whom they conducted the daily business of living: Doctors, dentists, shopkeepers and so on. Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in the community. Surrounded by staff and others receiving the same services, people with disabilities are relegated to roles of "clients," "service users," or "program participants." Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Bercovici (1983) found, for example, that a large number of adults with mental retardation did not view themselves as living in the "normal" community, but rather in a parallel, community-based but nevertheless insitutional setting. Her subjects compared their lives in the community to that of the institution with the same staff, program structures and hierarchy of control. Such occurrences are not infrequent and the informants in our study had had similar experiences. They take place so often that they form a pattern, i.e. The "normal" existence for people with disabilities (Blatt & Kaplan, 1966; Blatt, Ozolins & McNally, 1977; Wolfensberger, 1975; Wolfensberger & Thomas, 1983).

The role of human services in the lives of people with disabilities often results in unnecessary and extensive control over at least part of the persons' lives. The staff have the authority to determine with whom a person will spend time. Agency staff may then try to set restrictions on what the clients can do with their friends and may actively try to end some relationships. Other programs try to turn friendships between typical persons and clients into formalized volunteer relationships. Such efforts make the volunteers responsible to the agency and weaken their bonds with their friends.

While all of the four informants with disabilities did have some experiences in a freely-given and chosen relationship with someone, they did not enjoy the same number of such relationships as did the informants without disabilities.

For the informants with disabilities, the most successful way to meet new and different types of individuals was to be introduced to them through their friends without disabilities.

2. The possibilities for friendship between people with and without disabilities

Despite the differences between opportunities and experiences, at least some people with disabilities have successfully formed friendships with people without disabilities. Through studying established friendships, we learn that both parties respect one another. The friends also experienced a mutuality in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship. This mutuality was expressed by the giving and receiving of emotional support and practical assistance, serving as an inspiration for each other, breaking rules together and by simply enjoying the time spent with one another.

Three of the people without disabilities met their future friends in situations where they were not identified primarily as "clients." One saw her friend with a disability primarily as a co-worker. Another saw a fellow parishioner with whom he shared some commonalities: They were both single men with spare time who wanted companionship—a buddy to hang out with. A third informant saw her friend mainly as an adult student like the many others who had taken her course. She also identified with her friend as a woman who had experienced oppression because of her gender. These perceptions helped pave the way for a friendship to develop. When people with and without disabilities go to school, work, attend church, live and conduct their lives side by side, the possibilities for friendship are enhanced. When individuals are in staff/client roles, it may be more difficult to establish personal relationships with each other. For two of the informants, these roles had to be transcended in order for their friendship to begin.

For it is when friendships continue in spite of the pain and disappointment, that something beautiful has been borne into existence.

Friends, not heroes

In our enthusiasm to support friendships between people with and without disabilities, there may be a tendency to inflate the existence of such friendships, to exaggerate the status of these friendships in the partner's lives and to overemphasize the effect or influence of a specific friendship in a person's life. There is documentation, however, of incredible efforts made on behalf of people with disabilities by their friends (Schwartz, McKnight & Kendrick, 1987). Bogdan (1987) describes how friends helped to reunite a family and built them a new house. One woman's life was literally saved when her friends saw to it that she was removed from the abuse and neglect that she was receiving in a nursing home (Forest & Snow, 1983; Perske, 1988). These stories of heroic friendship have served as sources of inspiration to quite a few people and have been used to illustrate the importance of friendship for people with disabilities.

While many would consider friendship in our lives as essential, it cannot serve as the panacea for all of our problems. As in all other interpersonal relationships between human beings, friends may sometimes disappoint and hurt each other. Friends sometimes fight with each other and do not always make up. Some friendships end while others may not meet the expectations and hopes of one or both of the people involved in the relationship. In the desire to encourage friendships, and to publicize certain stories in order to serve as a model for others, the mystifying and mythologizing of the relationships that do exist must be avoided. To turn the real struggle of people's lives into fables is to strip the people of their reality and the true power of the friendships. For it is when friendships continue in spite of the pain and disappointment, that something beautiful has been borne into existence.

References

Bercovici, S.M. (1983). *Barriers to normalization—The restrictive management of retarded persons.* Baltimore, MD: University Park Press.

Blatt, B., & Kaplan, F. (1966). *Christmas in purgatory: A photographic essay on mental retardation.* Scituate Harbor, MA: Allyn & Bacon.

Blatt, B., Ozolins, A., & McNally, J. (1979). *The family papers: A return to purgatory.* New York, NY: Longman.

Bogdan, R. C. (1987). *Georgia Advocacy Office site visit report.* Syracuse, N.Y.: Center on Human Policy.

Bogdan, R. C., & Taylor, S. J. (1987). Toward a sociology of acceptance. *Social Policy.* Fall. 34-39.

Bogdan, R. & Taylor, S.J. (1989) Relationships with severely disabled people: The social construction of humanness. *Social Problems.* 36 (2). 135-146.

Edgerton, R. (1988). Aging in the community—A matter of choice. *American Journal on Mental Retardation.* 92(4), 331-335.

Edward, J., & Dawson, D. (1983). *My friend David. A sourcebook about Down's Syndrome and a personal story about friendship.* Portland, OR: Ednick Communications.

Forest, M. (1989). *It's about relationships.* Toronto: Frontier College Press.

Forest, M., & Snow, J. (1983). The Joshua committee: An advocacy model. *Leisurability* 10 (1), 14-19.

Perske, R. (1988a). *Circles of friends,* Nashville, TN: Abingdon Press.

Perske, R. (1988b). Friends circle to save a life. *Augustus.* xi(3), 9-15.

Perske, R. (1988c). Friends circle to save a life. *TASH Newsletter,* 14(1), 1-3.

Schwartz, D.B., McKnight, J.L. & Kendrick, M. (1987). *A story that I heard: A compendium of stories, essays and poetry about people with disabilities and American life.* Harrisburg, PA: Pennsylvania Developmental Disabilities Planning Council.

Strully, J. & Bartholomew-Lorimer, K. (1988). Social integration and friendships. In S. M. Pueschel (Ed.), *The young person with Down Syndrome: Transition from adolescence to adulthood.* Baltimore, MD: Paul H. Brookes. 65-76.

Strully, J., & Strully, C. (1985). Friendship and our children. *Journal of The Association for Persons with Severe Handicaps,* 10 (4), 13-16.

Strully, J. & Strully, C. (1985b). Teach your children. *Canadian Journal on Mental Retardation,* 35(4), 3-11.

Taylor, S. J., & Bogdan, R. (1987). *On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance.* Syracuse, NY: Center on Human Policy.

Wolfensberger, W. (1975). *The origin and nature of our institutional models.* Syracuse, N.Y.: Human Policy Press

Wolfensberger, W., & Thomas S. (1983). *Program analysis of service systems' implementation of normalization goals (PASSING).* Toronto: National Institute on Mental Retardation.

This article was prepared through the Research and Training Center on Community Living, supported by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research, through Cooperative Agreement No. H133B80048. No endorsement by the U.S. Department of Education of the opinions expressed herein should be inferred.

TONY SANTI AND THE BAKERY
THE ROLES OF FACILITATION, ACCOMMODATION, AND INTERPRETATION

Zana Marie Lutfiyya
Center On Human Policy
Syracuse University
February 1991

Preparation of this case study was supported in part through a subcontract to the Center on Human Policy, Syracuse University, from the Research and Training Center on Community Living at the University of Minnesota. The Research and Training Center on Community Living is funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (Cooperative Agreement #H133B80048). The opinion expressed herein are solely those of the author and no endorsement by the U.S. Department of Education should be inferred.

The author wishes to acknowledge Rannveig Traustadottir, John O'Brien, Bonnie Shoultz, Steven Taylor, and Janet Duncan for their comments and insights.

Tony Santi and the Bakery

I first met Tony Santi[1] at my office. He came on Monday afternoons, delivering bread. He helped Patti, who was in charge of the operation, by carrying up the boxes of bread from her car. He stood off to one side as she greeted people, exchanged gossip, and sold the bread. Tony is a short, slight man, usually wearing blue jeans and a t-shirt or a flannel shirt. He would nod, smile, and respond if someone talked to him, but generally he stayed in the background.

I had heard of the Bakery where he and Patti worked. It is not strictly a commercial enterprise. Founded about twenty years ago as an outgrowth of the Catholic Worker Movement, it was meant to provide employment to individuals who had been involved in the criminal justice system. Patti is a social and political activist, well known locally for her efforts in a number of peace and justice causes. Tony has a slight speech impediment. From his manner, and by chatting with him, I assumed that he had a mild impairment of some sort. I learned from a colleague who had met him before that he had once been in a state developmental center. I was intrigued with Tony and wanted to learn more about him and his background.

My interest in Tony was inspired by my participation in the Community Study. The Community Study is a five year project during which time a group of about ten researchers plan to meet and follow along about two dozen individuals with mental retardation/developmental disabilities. We want to learn about their place in the community, and who they know. This includes learning about the people with whom they are connected and the meaning of these connections and personal relationships to the individuals with disabilities.

This interest in what has been characterized as the informal, unpaid, or "natural" relationships of individuals with mental retardation has come directly out of the concern for the community integration of such individuals. In the past few years or so, there has been more of an emphasis on learning about, and facilitating the personal social integration of individuals with disabilities (O'Brien & Lyle O'Brien, in press; Wolfensberger & Glenn, 1973). A commonly held assumption is that many individuals with mental retardation and other developmental disabilities are isolated from their community, and do not know many people other than those who are paid to be with them in some capacity (Wolfensberger, 1987). This has resulted in efforts to establish regular contacts between people with disabilities and typical community members (Bridge & Hutchison, 1988; Cormier, Grant, Hutchison, Johnson, & Martin, 1986). The goal of these interactions is to promote close ties between disabled and nondisabled individuals and rests on the belief that such freely given relationships will lead to a more complete participation of individuals with mental retardation in society (Johnson, 1985; O'Brien, 1987; Taylor, Racino, Knoll, & Lutfiyya, 1987).

---

[1] Unless stated otherwise, all names of individuals, facilities, and agencies in this report are pseudonyms.

In establishing this research project, we gave ourselves the challenge to identify and contact individuals with disabilities outside of or with little contact with the formal human service system. We wanted to pursue the possibility that there were at least some individuals with developmental disabilities who had made a life for themselves, or who had been assisted to make a life for themselves, outside of the traditional community based service network of group homes/residential facilities and sheltered workshops/supported employment programs.

And that was one reason why Tony Santi intrigued me. As I chatted with him for a few minutes each Monday afternoon in the fall of 1989, I learned that he worked part time at the Bakery and lived in his own apartment. He had once lived in a large, notorious state institution for the mentally retarded, but had "escaped" (his term) and had moved back to his hometown of Syracuse. In the late fall, I asked him if I could interview him, starting early in the new year. He readily agreed, and added one proviso: that I would spend time at the Bakery. For as Tony said to me, "you can't learn about me without spending some time at the Bakery." This paper is an initial description of Tony, his background, and his life today, a large part of which is the Bakery and the people who work there.

Tony Santi: His Background

Tony is not very good at remembering dates or how old he was at the time any given event. But at his most recent birthday party celebrated at the Bakery, I found out that he was 37 years old. The lack of clarity of specific dates makes compiling a personal history of this man somewhat difficult. But after talking to Tony and others, it is clear that there are some distinct "chapters" of his life: his early days in Syracuse; the "institutional school"; living on the streets; the prison; and living on his own.

The Early Days in Syracuse

Tony grew up on the North side of Syracuse until he was about 8 or 9 years old. The North Side is a working class, blue collar neighborhood of mostly German and Italian American families. Tony lived here as a small child with his parents, brothers and sister.

Most of what Tony recalls from his childhood are stories and big events. Like the time his father took the whole family apple picking one fall. The family, busy filling up their baskets, didn't notice the owner approach and warn them off. The farmer chased the Santi family off his land, firing his shot gun into the air for effect. Instead of paying for the privilege of picking the fruit, a typical practice in Central New York, Mr. Santi had simply pulled up to an available field and had his family help themselves. Tony laughs heartily when he remembers how his father got his family into the car to drive off--with the apples. Tony missed the car and was running after it, trying to hold on, yelling, until his dad stopped to let him in.

Tony recalls his school days with much less relish. He went to a parochial Catholic school for kindergarten and the first grade, while going with his brothers and sister to catechism classes, or what he calls "church school." He had a difficult time in school, a hard time learning how to read and keep up with the classwork. According to Tony, the teachers at the parochial school told his family that he was a "hard case" who needed to be sent to the institutional school in order to receive an education.

The Institutional School

It may be hard for some readers to think of a state institution for the mentally retarded as a boarding school, but that is how these facilities seem to have been described to families in the 1950s in this country. It is undoubtedly more palatable to think of the facility where one's child is living as a boarding school where s/he will receive a useful education. However, it is clear from Tony that he does not regard the Empire State School (as it was then called) or the Empire Developmental Center (today's name) as anything but a prison.

The state institution to which Tony was sent once housed thousands of residents. It was extremely difficult for Tony to try to describe and talk about his years in the institution, except to say what a bad place it was. As he told me in our first interview:

> *Recently, I read in the paper where they were making that place into a prison,* like up at Kingstown. And I said to myself, well at least they got that right. That's what it is, a prison, and no school. At least now they are being honest with the name. It is a bad place.

When I told him that at least some of the original residents were still living on the same grounds, adjacent to the new prison, albeit in new cottages, Tony shook his head and replied, " Well, then I feel sorry for the poor bastards that are still in there. No one should have to live like that, nobody, no way."

Tony's father did not have the heart to take him to the institution, so he got Tony's brother to do so. When asked to describe how the institutional school was bad, Tony told about being mistreated and abused by both the staff members and some of the other residents. Tony, a small child, recalled often being picked on because of his size. He soon developed a reputation as a "runner," and became known for his various escape attempts.

The first time that he ran away was during a visit from his father. His father had taken him to a nearby town for an ice cream cone. The stand did not have a bathroom, so Tony told his father that he was going across the street to use the facilities there. Tony walked away, using the gas station as cover. It took his father a few minutes to realize what had happened, and then he got into his car and started back down the highway, searching for Tony. Tony, already on the road trying to hitch a ride, saw his father's car. He jumped into the ditch until his dad's old Chevy had passed him by. After the car had passed, Tony got out of the ditch and waved goodbye to his father.

As Tony tells the story, it was here that he made his first mistake. He hitched a ride back into Syracuse and returned to his neighborhood. He did this even though he had been warned not to by an experienced friend, also a runner, who had told him that one's home is the first place where the officials came looking for one. In those days, as today, institutions in New York state are patrolled by security guards who wear official looking uniforms with badges and drive patrol cars painted to resemble police cars. These security people are referred to as the "state school police," or the "institution police." After returning to his neighborhood, but not to his parental home, Tony learned that it had been his parents who had called state officials and informed on him.

Tony spent several years at the institutional school, nominally attending classes, and working, typically in a variety of janitorial positions. He was moved to several different buildings, and these moves came right after he had run away and then been returned to the institution. When Tony turned 21, he was "paroled." On yet another escape, Tony had returned to his neighborhood. There a friend of the family who apparently kept in touch with Tony and knew his whereabouts, told Tony to go look up his father, who had just gotten word that Tony was to be paroled. Tony and his father returned to the institution and Tony picked up his discharge papers. To his surprise and dismay, Tony now learned that his father was not prepared to let Tony return home. Tony was now on his own.

On the Streets

After being discharged from Empire in 1974, Tony lived "on the streets." He moved into a halfway house in Syracuse, but only stayed there until early 1975. He then lived in a series of apartments, on the street, and in other people's homes. During this time he spent a year in jail for theft, and then a couple of years later, he was sentenced to serve two concurrent two-year sentences in the prison at Kingstown.

It was during these years on the street that Tony met up with and became connected to the individuals with whom he now associates. These are folks who are loosely affiliated with the Catholic Worker Movement and/or some of its projects in the Syracuse area. It was also at this time that Tony got involved with a number of individuals who had shady pasts and careers. Tony admits to selling stolen property, and getting mixed up in some unusual land and house sales. Throughout this period he would get into minor trouble after making threats by telephone or in person to his "business partners." He also talks about destroying and vandalizing property (houses and cars) of some of these individuals. He was up before a judge for a number of these offenses.

On the other hand, Tony became connected to a number of welfare agencies and human service workers. He went to a soup kitchen for his meals. Someone at the kitchen helped Tony to apply for welfare. This soup kitchen was also operated by Catholic Workers and their affiliates. Carla, a woman who was working at the soup kitchen and living in the halfway house, helped Tony move in there. It was at the halfway house that Tony met Father Bryan who was living there himself. The primary mission of this place was to serve men who had been in jail or in trouble with the law. According to Tony, Father Bryan thought that the halfway house was not a suitable place for Tony, so he helped Tony locate a series of small apartments to live in. Gradually, Tony became adept at doing this himself. But he continued to move constantly every few months or so. Father Bryan also employed Tony to clean the halfway house, and accompanied him on his various court appearances.

Tony told me a few stories about these days. He had gone over to a business partner's house, and had broken a window with a large stick, calling to the man to come out and face him directly. The man called the police. As Tony saw the cruiser turn down the street in answer to the call, he headed out, and:

> I was cutting through the weeds and all that to get down by a mall. The cop was chasing me, and then he tripped. His face went into the mud. And then I walked over to him to make sure he was okay. So I reached my hand out to him and I says, "Do you want me to help you up?" And he says, "Are you one little son of a gun." And then I am looking at him, at his face, and I just couldn't help laughing, I was laughing so hard I just couldn't run anymore, and I said, "Okay, you got me." And then he said to me, "I got to admit that you are a fast runner." And I said, "Well, you would have caught up if you hadn't of tripped."

Tony was in and out of the municipal jail for thirty or sixty days at a time for a variety of these petty misdemeanors. When Tony runs into the lawyers and court officials from that period, they remind him of several incidents like the one above. Tony tells most of these stories now, chuckling, able to laugh at himself. But he can still get angry. He recounts a number of incidents with his court appointed attorney which left him feeling unrepresented, and disappointment over the betrayal he experienced at the hands of his numerous business partners. Today, Tony explains his past run-ins with the law as the result of a bad influence in his life. "It was like some kind of an evil thing that I had in me to do that."

Throughout this period, Father Bryan remained in contact with Tony. He accompanied Tony to all of his court appearances, often wearing his clerical collar for effect. Father Bryan became well known as an advocate and friend of Tony's. As Tony said, "Judges knew there was a slight problem whenever Father Bryan came to court." Their relationship has endured over the years, and today Tony says that Father Bryan is, "one of my best friends. We go way back."

Before going to jail, Tony belonged to two different but related worlds. The first was the world of petty crime, theft, and selling stolen objects. The other was the world of those committed to trying to help out people who were poor, living on the street, and having difficulties with alcohol or the law. On the scale of things, Tony's forays into crime were not "big-time," but as what was once known as a "bum," he had been inducted into a street society that included both of these groups of individuals and networks.

Doing Time

When Tony was finally sentenced for a longer term jail sentence, it was Father Bryan who convinced the judge to let Tony serve the four year sentence in two separate terms, concurrently. This allowed Tony the opportunity to do his time in a medium security facility nearby, rather than being sent to another part of the state. Father Bryan visited him regularly in jail.

According to Tony, it was around the time of his incarceration that Father Bryan became Tony's representative payee. This meant the Father Bryan controlled Tony's welfare monies and disbursed the monies to Tony every month as he needed them. So Father Bryan took care of Tony's financial affairs, such as they were, while Tony was in jail. He also visited Tony once a week, and made sure that Tony received some of the amenities that only outsiders can provide to inmates (like extra snacks and cigarettes).

On His Own

Tony acknowledged that being incarcerated was very tough, and it is definitely a period of his life that he prefers not to talk about. When Tony was released, he resolved to stay out of trouble. He planned to do this by living alone and staying away from housemates (originally, it was some housemates whom he went into business with). He also decided not to get a telephone, and thus avoid the people with whom he had gotten into trouble before. Father Bryan remained his representative payee, and stayed in close touch with Tony.

Like the earlier time when he lived on the street, Tony found himself a series of apartments to live in. He describes all of them as having been small, cheap places that he could afford on his own. He initially worked for Father Bryan, running errands for men who were in the local detention center waiting to be tried or to be bailed out. This meant that he would purchase the cigarettes and snacks that these men could receive, take down bail money for the low bails (e.g., fifty dollars), mail letters and so on.

Tony met the people at the Bakery when he helped Father Bryan deliver their bread once a week. Eventually, he got himself a job in the Bakery. In the beginning, Tony started out by bagging the bread, that is putting the cooled loaves into plastic bags, labelling them and then sealing them. But his role quickly expanded. As Tony tells it:

> One guy broke me in on the cinnamon buns, and how to seal them packages tight. And then from that I was doing the dishwashing and from the dishwashing it extended into a lot more heavier work.

Today, his official job title is "Jack of all trades." He is proud of that title, which is printed in the brochure about the Bakery. He cleans but also helps with all aspects of the bread production, and is one of the few people who can easily lift the heavy, wet dough. The Bakery closes during the summer for three months. During this time, Tony tries to earn money as a janitor, mowing lawns, and other odd jobs which are generally arranged by others at the Bakery.

The Bakery

The Bakery was first started by two Catholic workers who wanted to create an economic enterprise that employed people often excluded from the world of work. Father Bryan became involved in the early days. As part of the "crowd" associated with Father Bryan and the halfway house, Tony visited the Bakery on a number of occasions. Tony, along with about a dozen others, works at the Bakery two of the three days that it is open, on Mondays and Fridays.

The Work

As its name implies, the Bakery is just that, a bakery that produces a couple thousand loaves of bread each week, which are then sold. It is a small operation, run by a dozen workers and volunteers. Workers range in age from their early twenties to their late eighties. And because of its ties to the Catholic Worker Movement, the Bakery claims a mission that is more than merely baking bread. The work of the

Bakery includes both the baking and selling of bread, and an attendant activity that is spiritual in nature: the rebuilding of individual lives as well as creating a community life.

This dual nature of the work in the Bakery is reflected in the language that the people use there. First are the terms that deal with the actual preparation of the bread itself: making the dough, cutting it, rolling it out, the first and second rise, and so on. But many of the workers at the Bakery are also aware of and consciously use the metaphor of making bread in additional ways. When classes of schoolchildren come to spend a morning at the Bakery, they are told that the yeast is alive, a living organism, and that this causes the bread to rise. This is compared to the actions of humans who through a small effort in the right place and right time, can cause ferment, and some positive change to occur.

In this paper, while I will not go into any detail describing the physical work of baking, I do want to describe this second aspect of the work that takes place at the Bakery.

The People

Individuals with different backgrounds and experiences work at the Bakery. The "core members" of the Bakery are Carla, Liza, Olivia, and Father Bryan. Carla has worked at the Bakery since it first opened, and lives in the Halfway House that Tony stayed in many years ago when he left the institution. Carla packs the bread for delivery. Liza, now the manager, has also worked at the Bakery since the early days. Although Liza maintains that her main concern is bread production and running the Bakery as a business, she carefully orchestrates the work and involvement of individuals like Tony. Liza's eldest daughter, Pam, married and with a family of her own, works at the Bakery once a week.

Olivia is the matriarch of a large family that is involved in many of the activities of the parish where the Bakery is located. Olivia is the assistant manager, and is in charge when Liza is away. Father Bryan is responsible for much of the distribution of the bread.

Tony and Danny are the youngest of the regulars who work at the Bakery. Danny is a quiet man who keeps to himself. He bags the bread. He occasionally misses work, due, it is believed, to his glue sniffing. When this happens, Father Bryan is dispatched by Carla to seek him out and make sure that he is okay.

In addition to these regular workers, the Bakery hosts many visitors. Most are schoolchildren who take a field trip to spend the day. Some individuals volunteer their services at the Bakery for a number of years, as many of the drivers who deliver the bread do. All visitors are taught the philosophy of the Bakery: that baking bread is both a practical and symbolic activity.

Baking Bread: Building Connections

The important work of the Bakery is not simply baking bread, it is also how the baking is done. All of the workers have valid and valuable roles in this work and everyone's contribution is necessary. The bread is baked by individuals who could not do their work without the presence of the others. Baking bread is one way to establish and maintain a small community of people bound by common purpose and work, at least for two days a week. Involving everyone in a valid way is an unspoken and not highly visible effort at the Bakery and can be a real challenge. Many of the workers would not generally be viewed as highly skilled or capable on the open job market. While many of the examples presented here are taken from Tony's experience, the efforts at facilitation, interpretation, and accommodation are extended to everyone at the Bakery.

Facilitation

The word facilitation[2] is used here to refer to those activities that help to bring people together. This might involve teaching either a disabled or nondisabled individual a particular skill or response. The things that are learned may be used in an actual interaction with another individual or simply to increase the opportunities for people to get together. Facilitation can be used to smooth over ruffled interactions between people. The use of facilitation is not restricted only to people with disabilities. But when it is planned, the effort is in making a particular interaction or relationship go well. The purpose of this activity is not to teach people with disabilities certain skills that they can then generalize to other situations.

---

[2] The author acknowledges Rannveig Traustadottir and her (so far) unpublished analysis on the facilitation that some personal assistants perform on behalf of the individual with disabilities whom they are working for.

The continual and ongoing effort of both Liza and Olivia in trying to involve Tony in a number of "wholesome" social activities falls into the category of facilitation. These include invitations to monthly suppers that are held at the parish, coming to mass, and other occasional social activities and events that take place.

Olivia tries to facilitate certain interactions between me and Tony. On several occasions, she tries to get me to assume another role than that of a researcher with Tony. She calls me his friend (despite my corrections otherwise) and at least twice asks me to "reinforce" something with him, typically something that she thinks would be good for him. For example, she approached me on a few occasions and openly wondered about where Tony should live, and could I help him find a group home to live in, so that he wouldn't have to be alone.

Interpretation

Interpretation is used here to refer to those occasions where a person is presented in a positive and a enhancing way to others (Wolfensberger, 1972; Wolfensberger & Glenn, 1973; Wolfensberger & Thomas, 1983). To interpret someone in an enhancing way is not only nice for the person, but it can indirectly promote further positive interactions between individuals with and without disabilities. The individual with a disability is portrayed to others as being interesting; both worthy and capable of establishing a relationship.

One day, Tony was being teased by others at the Bakery. Olivia interrupted and asks if people knew that Tony had saved a man's life. His next door neighbor tried to commit suicide by turning on the gas in his apartment, and then starting a fire. Tony smelled it, and tried to enter the man's apartment. He then called the police and got the caretaker. The two of them broke down the door and rescued the man. As he was telling the story, Olivia suggested what he should tell next, so that no details would be missed. By the end of the story, Tony was downplaying his role, but others contradicted him and told him how brave he had been to act on another's behalf with little or no thought to his own safety.

Accommodation

Accommodation refers to the actual changes in the physical or social environment that makes it easier to involve an individual in some way. The most obvious case of making an accommodation would be to add a ramp and renovate washrooms. It is typically this act of making a physical accommodation that gets defined as the essence of integration and helping someone to fit in. Physical accommodations result in physical integration, but the interpretation, facilitation and accommodation in the social environment of a person's social integration, lead to the valued participation in a typical activity or interaction.

An example of this occurred when Liza arranged a part time job for Tony. The church where the Bakery is located needed someone to clean up after the congregation's monthly community suppers. Olivia and Liza thought that Tony would be an excellent and obvious choice to take on this role. The suppers end at nine p.m., so the two women thought that Tony could come in first thing Wednesday mornings to clean up the hall. Tony refused the job regretfully, because he could have used the money. But he did not want to be in the church on Wednesday as he didn't get along with a couple of the people who would be there.

Liza devised a plan whereby Tony would come in towards the end of the supper, have something to eat (he generally avoids these suppers too), and then stay to clean up. It would be late, 9:30, but he was close to his own home and would not be at risk to walk the few blocks at that time of night. Tony agreed to the idea of coming in the evening, and then Liza convinced Father Bryan of the scheme. Tony is not allowed a key to the church, but Father Bryan could lock up, leaving one door that Tony could exit the church from, with the door locking itself behind him. As Liza reasoned with Father Bryan about the change in schedule to suit Tony, she suggested that this would be one way to get Tony back to the community suppers and with people. Both Tony and Father Bryan agreed to Liza's plan although they had different reasons for doing so.

Conclusion

The Bakery fills more than one function in the lives of the people involved with it. It is a place of work, and of meaningful occupation. It is a place to get together with other people for companionship. It is a place for like minded people to get together: activists in the peace and social justice movement, those involved in their local parishes and individuals who have faced a variety of difficulties (e.g., substance abuse, incarceration, poverty, homelessness, unemployment).

The people at the Bakery try to reach out to people in the community in order to provide food and sustenance. One day a week, free bread is available from the Bakery to local soup kitchens and food pantries as well as anyone who happens to stop by. As one worker said, "On free day, you get the bread for free. It's a statement. We all need bread to eat, and when we eat the same bread, it's a statement that we are all the same."

Another example of this attitude was demonstrated the day a high school student came in and asked how much bread he could buy for 47 cents. Liza told him to put away his money and help himself to a couple of slices of bread and butter. As she said, "we have bread to share."

But there is a tension at the Bakery between the efforts at reaching out into the community and maintaining a level of bread production and sales in order to keep the Bakery going. This dilemma was articulated by a long-time baker, who is disappointed in what she sees as commercialism overtaking the real purpose of the Bakery as a place for people to come together and associate with each other.

> That's what people today need. Boy, I wish we were more like that here. No, its just not the way I had envisioned it. The commercial has won out. We are so commercial here. I had planned a bakery with a full time day care. Women could come and leave their kids, help out here, or just bring lunch and visit with each other. I knew a couple of women like that, they would have come. But our production has driven out all this kind of stuff.

On the other hand, several of the people working at the Bakery want to earn the minimum wage or better. This means that a certain amount of bread must be made and sold. As Father Bryan stated:

> We have introduced much more of an economic thing...than used to be the case. People get a stipend for bread baking which is probably more than minimum wage. [To do this] you have to...get enough production...and distribution...to meet the overhead. It changes the atmosphere.

This dilemma will not be easily resolved as those at the Bakery wish to provide a workplace and a place where often forgotten individuals would be welcomed. But for Tony and others, working the Bakery provides both meaningful employment and meaningful association with others.

References

Bridge, N. J., & Hutchison, P. (1988). Leisure, integration and community. Leisurability, 15(1), 3-15.

Cormier, L., Grant, C., Hutchison, P., Johnson, N., & Martin, L. (1986). Facilitating friendship and integration for adults. Leisurability, 13(1), 22-26.

Johnson, T. (1985). Belonging to the community. Madison, WI: Options in Community Living and Wisconsin Council on Developmental Disabilities.

O'Brien, J. (1984). A guide to life-style planning: Using the activities catalog to integrate services and natural support systems. In B. Wilcox & G. T. Bellamy (Eds.), A comprehensive guide to the activities catalog (175-189). Baltimore: Paul H. Brookes Publishing Co.

O'Brien, J., & Lyle O'Brien, C. (in press). Members of each other: Perspectives on social supports for people with severe disabilities. In J. Nisbet (Ed.), Natural supports. Baltimore: Paul H. Brookes Publishing Co.

Traustadottir, R. (1990). Supports for community living [Unpublished case study].

Taylor, S. J., Racino, J. A., Knoll, J. A. & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Wolfensberger, W. (1972). Normalization. Toronto: The Canadian Association for the Mentally Retarded.

Wolfensberger, W. (1987). The new genocide of handicapped and afflicted people. Syracuse, NY: Author.

Wolfensberger, W., & Glenn, L. (1973). Program analysis of service systems, PASS (3rd ed.). Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Thomas, S. (1983). Program analysis of service systems' implementation of normalization goals (PASSING). Toronto: National Institute on Mental Retardation.

perspectives
On Community Building

Members of Each Other

Perspectives on Social Support for People with Severe Disabilities

John O'Brien and Connie Lyle O'Brien

© 1991

RSA
Responsive Systems Associates
58 Willowick Drive • Lithonia, Georgia • 30038-1722
Phone/fax (404) 987-9785

Contents

Introduction ---1

Membership denied: The consequences of exclusion -------------4

Known as a member ---9

  The varieties of social support---------------------------------------10

  Controversies around social support -----------------------------12

    Should we say that mothers provide social support? -------13

    Can people depend on social support for their future? -----15

    How do human services influence social support ------------19

    A fertile dilemma ---22

Building community by expanding membership------------------23

  Citizen advocacy ---25

  Connecting people to community associations ----------------29

  Circles of Support ---35

  How human services could help------------------------------------40

Paradoxes of community building ------------------------------------42

Conclusion ---45

References ---46

This chapter has been shaped by continuing discussions with Kathy Bartholomew-Lorimer, Betty Ferris, Marsha Forest, Gail Jacob, Zana Lutfiyya, John McKnight, Beth Mount, Jack Pearpoint, Patricia Powell, Judith Snow, Steven Taylor, and Alan Tyne.

Preparation of this chapter was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

The way we are, we are members of each other. All of us. Everything. The difference ain't in who is a member and who is not, but in who knows it and who don't.

*-Burley Coulter**

What can it mean to know that we are members of each other? In his stories of the Port William membership, Wendell Berry hangs the possibility of civic life on the answer people make to this question.

People experience different ways of belonging to each other. They speak of others as kin, as friends, as co-workers, as neighbors, as belonging to the same association or congregation, as sharing a common interest, as being "regulars" (like a regular customer in a tavern or a regular visitor to a park). Shaped by culture and personal history, each of these different relationships implies privileges and obligations specific to its participants. Most everyone identifies someone as a friend, but each friendship takes its own shape and meaning. For each person, these different kinds of belonging form the context for social support.

Good lives for people with severe disabilities depend on whether they are recognized as members of the social networks and associations that constitute community. People recognized as members benefit from everyday exchanges of support that create opportunities to play socially valued roles and chances to form personally significant relationships. People excluded from membership risk loneliness, isolation, and powerlessness.

Because people with severe disabilities cannot take membership for granted, those concerned to build stronger, more inclusive communities must consider how people deny membership, the resources that membership can offer, and the ways membership can be established.

Mostly, knowledge of our membership in each other lies beneath words, in everyday habits. People spontaneously acknowledge membership in culture, neighborhood, association, and family through signs and rituals that signal belonging and set common boundaries. People say "we" with nuances of behavior from their way of telling visitors goodbye to their way of offering a friend help.

People usually stop to speak about membership only when it becomes problematic in some way. They look for words when they believe their conduct disturbs a common sense of obligation (as Burley Coulter does in *The Wild Birds*), or when they look for a way that people disconnected from one another can form a larger membership (as Paul does when he writes to the Ephesians in the letter Burley Coulter echoes). If people try to talk about shared membership, it's hard to find words that adequately match feelings of belonging or exclusion.

---

* In Wendell Berry *The Wild Birds* (p. 136)

Probably this poverty of language reflects cultural devaluation of relationships (Gilligan, 1982). Maybe, it shows that our language has evolved more slowly than our collective need to think explicitly about the kind of relationships that past generations of humans might have taken for granted. Anyway, the search for adequate terms becomes more difficult the more one's pattern of memberships diverges from Burley Coulter's. His memberships grow from his lifework of farming in and around a small village. He knows the history of most of the people he belongs with. He meets the same people in different contexts of membership, exchanging farm work with men alongside whom he hunts and socializes. Unlike Burley Coulter, many people rely significantly on cars and telephones to maintain their social worlds. Their different memberships occur in widely separated locations. They know little of other's history beyond the particular circumstances of their meeting. Their social networks include many people who would be strangers to one another if they happened to meet. Such loosely tied and dispersed memberships form the context for important personal relationships and mutual obligations the same as more tightly linked networks do. But they are hard to talk about.

The difficulty of finding words to reflect the web of connections that sustain our lives can be awkward in personal conversation. But when talking face to face people can repair imperfect communication with redundancy, metaphor, inflection, and movement. When words fail, we get by with inarticulate gestures or poems.

However, the lack of words to speak about and thus understand shared membership becomes crippling when people enact policies whose effects depend fundamentally on the nature of social relationships. Here, unwillingness to constructively face our inarticulateness hurts. Of US policies designed to alleviate poverty, strengthen families, deinstitutionalize, assist elders, and prevent mental and physical maladies, Seymour Sarason and his associates (1977) observe:

> *...the failure, absolute or relative, of most programs in human service (and the resulting cynicism about mounting any successful program) is in large measure due to unexamined, oversimple, and invalid conceptions of the nature, extent, and bases of human relationships.* [14]

Of British policies designed to increase community care for elders and disabled people, Martin Bulmer (1987) says:

> *...in significant respects, 'community care' policies rest upon fallacious common sense assumptions which are wrongly presented by policy makers as sociological truths. As a result there is a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services...* [ix]

The moral seems simple. To reduce the chance of unpleasant and dispiriting policy outcomes, learn more of the nature, extent, and bases of social relationships. Sensible as it may be, this injunction is less academic than it is epic: not "Go to the library and then do the needed research and bring back the unshakable facts." but, "Bring me the ruby slippers." Earning significant knowledge of important social relationships means learning a bit at a time through reflection on action which tests character as much as intellect.

Like others excluded and oppressed by shared denial of membership in each other, people with severe disabilities can teach a good deal about the social relationships at the foundation of civic life. To learn, one need only get involved: listen, look, try to understand situations in terms of shared humanity, and respond actively to invitations for personal engagement and civic action. Through this discipline, people with disabilities teach on three topics:

☐ The consequences of long term exclusion from membership

☐ The benefits implicit in recognition as a member

☐ Some of the explicit work necessary to change patterns of exclusion so that a person moves to being known and treated as a member

Membership denied: The consequences of exclusion

Michael* lived in an Ontario provincial institution before moving into a community residence, a job in a market, and an active role in a self advocacy group.

He remembers life in the institution as organized around control.*"The worst thing ...was havin' staff around all the time. Not goin' anywhere without staff. Doin' things they wanted you to do, not what you wanted. And gettin' blamed for stuff."* [p.40]

And punishments: *"They made you dig for worms. It's a punishment... You hadda put your face right in the ground and dig worms, then you hadda put 'em back when you was through..."* [p.41] *"I'm thanking God they're closin' that place...How would you like somebody to strip you bare naked and make you walk round the floor, around and around? I don't know why they did that, they were crazy..."* [p.38]

Though his life has changed remarkably for the better, his experiences have left their mark: *"The scare is still in me after all these years."* [p.38] (Melberg-Schwier, 1990)

Seymour, a professor of psychology, began his career at Southbury Training School, an innovative institution in his day. Reflecting on residents' desire to return home despite the "obviously" superior living conditions at the institution, he notes that, at the time, he considered this desire a symptom of retardation, *"...paternalism rendered you incapable of grasping and comprehending the world as it is experienced by those for whom you feel responsible... You thought you were explaining human behavior, unaware that the explanation rested on an unexamined axiom: we and they had nothing in common. If we were in their place, we would get on our knees and thank God that we were placed at Southbury. Yes, the residents were human, but we could not accord them feelings and longings that follow separation...* [p.149] (Sarason, 1988)

Both Michael's terror of mindless, dehumanizing control and Seymour's missed opportunity for understanding arise from their unthinking participation in settings that enact the moral exclusion of people. Such places discourage those employed as staff from knowing that they and their charges are members of one another. At the same time, these places reinforce the physical and social distance between their inmates and those people others easily recognize as "one of us." By so doing, they enforce and ratify the perception that people with severe disabilities should live outside the boundary of membership. Inside the boundary, people may dislike or disapprove of one another, people may have conflicts, people may avoid one another, and people may let one another down. But within the boundary of acknowledged membership, people see one another as approximately equal, they see the possibility of mutuality, and they consider others entitled to fair treatment and a share in common resources.*

---

* In presenting and discussing examples, we refer to people by their first names. This is because people have different concerns about confidentiality. Some people would be happy to be known by their full real name, others prefer not to be so identified, other have already acquired pseudonyms from other authors. We have chosen to treat people equally by using only first names. We hope that this will not seem disrespectful.

The conflict between some parents of severely disabled children and some of their professional advisers highlights the contrast in understanding between those who know someone belongs to them and those who deny shared membership. One parent speaks for many who resist professional pressure to set someone outside their membership,

> *"The doctors told us he would never learn anything or be anything. They said, 'Put him away and forget him.' But he was ours, so we ignored them and took him home. They said he'd never roll over, but he can walk. They said he'd never talk, but he has even learned to read a little. They said he'd never feed himself, but now he has a job in a restaurant. They said he'd be a burden, but it's people like them, who still don't see his humanity, that burden us most. Why can't people welcome him for who he is?"*
> *(O'Brien, 1988)*

Setting some people apart may be one of humanity's most common boundary defining mechanisms. Groups can say who they think they are by contrasting themselves favorably with inferior outsiders. Groups can define their rules of conduct by pointing at the immoral or outlandish customs of foreigners. Groups can generate strong feelings of closeness and common purpose by defining an enemy whose otherness is terrible and menacing. Groups can defend individual members from frightening impulses by projecting the unacceptable onto outsiders. In each case, the identity of an *us* depends on maintaining a depersonalized *them*.

But why should disability create a *them*? Michael was born among people with a strong sense of *us*, but he became one of *them*, even to most members of his family. How does his learning difficulty lead to a common sense that he is not one of our kind but someone who will be happiest apart from us, with his own kind?

Why can't some people recognize disabled people as belonging to them? When citizens of a community shaped by the moral exclusion of people with disabilities stop to think about it at all, they justify exclusion variously: people with disabilities have incurable sicknesses requiring continuous special treatment; they are dangerous to ordinary people or threatened by ordinary people's insensitivity; people with disabilities lack full humanity because of missing abilities and defective sensibilities.

---

*For a helpful general discussion of the causes and consequences of moral exclusion, see Opotow (1990).

Whatever the reason, those morally excluded as "not one of us" live outside the boundary within which positive values and ordinary considerations of fairness apply. At its historic extreme, moral exclusion led to systematic killing as a legally and professionally sanctioned medical treatment of people with severe disabilities (Gallagher, 1989).

In its everyday reality, denial of membership decreases severely disabled people's power to pursue their own goals and increases their vulnerability to dehumanizing, or neglectful, or abusive treatment. Sometimes predators victimize people with disabilities, but people who mean well can also diminish excluded people's humanity. As Connie Marteniz (1988) says of her experience,

> *"So when I was growing up everybody either thought they had to take care of me, like my parents and my brothers and sisters, or they pushed me away, like some of my relatives and most of my teachers who stuck me out of the way...*
> *My parents always had a dream for my brothers and sisters for when they grew up, but nobody ever had a dream for me, so I never had a dream for myself...*
> *Quality of life would make a mother support her daughter [in having and pursuing a dream]. That is very important. In my case, there was not support. When I was a child, the doctor said to my parents: 'You may have a dream for a perfect child, but forget about that. The case is you parented a broken child.' And that was Connie."* [p. 1-2]

When professional service providers set up a program to assist morally excluded people, they often mindlessly follow this recipe: group outsiders together, set them physically apart, isolate them socially, amplify stigma and arouse a sense of differentness, control the details of their lives (often in the name of therapy), enforce material poverty as a condition of assistance, offer relatively greater benefits to those clients who seem more like "one of us" and less to those apparently less familiar, and expect obedience and gratitude in return.

Though institutional settings typically express this pattern of denied membership, service reforms often do too.

John Lord and Alison Pedlar (1990) conducted a follow-up study of the quality of everyday life for 18 of the 260 people moved into small community group homes as the Government of British Columbia closed its institution at Tranquille. Like about 40% of the people deinstitutionalized by this initiative, these 18 people all have some continuing contact with at least one family member. Four years after moving, 8 people have only one person apart from paid staff in their social network; the other 10 people have 2 or 3 people in their social network. Typically these network members are family and former staff: family members, usually parents, remain people's most frequent contacts (they visit 14 of the people at least once a month) and 5 people have a friend among present or former staff members. One person knows a community member who was recruited to befriend him; one person's sister has actively included him in her network of activities and relationships; and one person is an active member of her church. People's most common roles outside their group homes and day programs are those of consumer and spectator: 2 or 3 times a week they visit restaurants and shops or movie theaters or bowling lanes, usually as one among a group of people with disabilities. Of the 18 different 4 person group homes people live in, only 6 homes enable resident participation in daily routines and actively support positive relationships among housemates. In 8 homes, people seem incompatible with one another and there is continuing tension or overt conflict between residents. Staff in a majority of homes spend most of their time either disengaged from residents or vigilantly monitoring and managing people's movements.

Margaret Flynn (1989) interviewed adults with mental retardation who receive some human service program assistance to live in their own apartments. Though almost all 88 people strongly prefer living independently to more supervised alternatives, she identifies 29 people who have been victimized in one or more ways, including: having money taken (17 people), being verbally intimidated by adults living nearby (15 people), having property damaged (12 people), and being mugged (2 people). She associates victimization with two human service program practices: channeling vulnerable people into undesirable neighborhoods and housing sites characterized as 'hard to rent', and failing to provide relevant training and support in presenting and standing up for one's self.

Summarizing his investigation of one region's implementation of supported employment, David Hagner (1989) reports that the alternative resembles the programs it was intended to reform. By observation and interview, he compared the experiences of non-disabled workers with the experiences of disabled people placed by a supported employment program. When performing the same jobs that human service staff choose for disabled workers to do, non-disabled employees regard those jobs as undesirable, temporary, and low status; non-disabled workers distance themselves from the job with such justifications as, "I'm only doing this temporarily." Non-disabled people do tasks in different ways than their disabled co-workers do because, usually for their own convenience, human service staff modify the ways disabled workers perform tasks: disabled people's jobs are "structured to an inordinate degree, almost fossilized, into an invariant sequence of tasks" [85]. Supervisors and co-workers express acceptance and approval of disabled workers, but regardless of this, job coaches attend to picking out and trying to remediate disabled employees' deficiencies and incapacities. Despite frequent, positive interactions among non-disabled workers at job sites, none of the supported employees participate much in these exchanges or form close working relationships because job coaches schedule the disabled worker's arrival, break and work time differently from those of their co-workers and because job coaches frequently insert themselves between workers with disabilities and their co-workers as buffers or interpreters.

A new program design won't make a significant difference until the people who plan it and the people who implement it confront their own program's potential to change all the details and still leave people with disabilities excluded from the circle of membership.

Unless people with severe disabilities, their allies, and those who serve them continuously widen their common recognition as members, the negative effects of moral exclusion will continue to undermine the quality of community life. Knowing another person as a member doesn't necessarily lead to treating the other person right, but such knowledge forms the foundation for civil and supportive relationships. Understanding that another person belongs to us doesn't necessarily disclose what to do when conflicts or difficulties arise, but such knowledge motivates action to strengthen common bonds rather than to ignore or sever them.

Recognition of membership grows as more and more people share the everyday experiences of schooling, working, playing, neighborhood living, and citizenship alongside people with severe disabilities in ways that highlight and strengthen the knowledge that we are all members of one another.

Known as a member

Jean and David are friends. In a book they wrote together, David writes about his life and they each talk about their friendship. In her account, Jean says, *"One Saturday David rode the bus over to see me and to see if there was anything he could do to help me. My mother had been bedridden for two years and I had been caring for her at home. There had been many difficult days but now she had pneumonia and there seemed to be no way she could fight it off. David stood beside her bed with me and spoke:*

"I am sorry you are hurting."

As he put his left arm around me and took my mother's hand in his right hand, he said what I really wanted to hear:

"It's OK to cry."

And we all three stood there and cried." [48] (Edwards & Dawson, 1983)

George attends a sheltered workshop. He lived in an institution, then in a group home, and now in an apartment. Based on his interest in bingo and with Bob's sponsorship, George became an active member of the Knights of Columbus. Over the three years of his membership, George has become more outgoing as he participates in a wide variety of activities, including working with his brother knights to run weekly bingo games. Recently George used his lodge contacts to become the top fund raiser for another local organization he is interested in. (Osburn, 1988; LaFrancis, 1990)

After 14 years in a sheltered workshop, a friend helped Kitty find a part time office job where she met and then became friends with Shirley. Kitty and Shirley frequently eat lunch together, and Kitty spends time with Shirley in Shirley's home. Shirley has helped Kitty expand her skills, take on additional job duties, increase her hours at work, and take a community college course. She says, *"[Kitty] is so eager to learn that I get excited showing her things... I get a lift out of that."* [9]

Shirley sees helping Kitty to improve her work performance as part of their friendship. *"I have taken it upon myself to worry about her as far as her livelihood... say if something happens to her parents... having her skills so that she could eventually go out and get a full time job and not having to rely as much as she does on other people... it's just something that I think about and I think that's one of the reasons I'm motivated to show her different things...* [11] (Lutfiyya, 1990)

The varieties of social support

Social support* is a convenient but abstract term which summarizes the effects of what people do for one another naturally, through everyday exchange of acknowledgement, information, emotion, and help. In discussing social support, some writers focus on immediate and specific results, such as help moving into a new apartment or consolation in time of grief. Others emphasize the cumulative effects of supportive ties on an overall sense of well being and health.

Passing the time of day with another person contributes to social support. Telling an acquaintance about a job opening contributes to social support. Listening to a friend as he struggles with a disappointment contributes to social support. Bringing in a vacationing neighbor's mail contributes to social support. Loaning a ladder to a friend contributes to social support. Running an errand contributes to social support. Bringing food to a wake contributes to social support. Helping a co-worker figure out a new task contributes to social support. Taking in a friend who has left her home contributes to social support. Hosting a celebration of a co-worker's achievement contributes to social support. Sharing a day at the beach contributes to social support. Visiting someone who is sick contributes to social support.

And, because the benefits of social support result from interaction, receiving each of these contributions also increases social support. In the enactment of shared membership, receiving assistance means as much as offering it.

---

* Some people use other terms like natural support, natural help, or community caring with a similar meaning. In this paper we generally refer to social support with the intention of including these other terms.

These personal exchanges occur routinely and, if asked, the people involved usually explain them by reference to their understanding of the relationship they share. Thus, David says that consoling Jean and her mother is part of being a friend, Shirley teaches and encourages Kitty because of her friendship, and Bob would probably explain his contribution to George's favorite charity as a consequence of their fraternal relationship. Social support can mean mobilizing substantial resources to help another through a crisis, but much social support manifests itself in actions that happen in such small, familiar ways that people don't notice them and even find it odd when someone calls attention to them (Leatham & Duck,1990).

Social support arises from at least four distinct experiences:

☐ Feeling attached to emotionally important other people

☐ Having the opportunity to engage in shared activities

☐ Being part of a network of people who can approach one another for information and assistance

☐ Having a place and playing a variety of roles in economic and civic life.

Thus people weave their memberships with four different threads.

Each of these four social resources contributes distinctly to well being, and one resource won't substitute for the others (Weiss, 1973). An active person may still feel deep emotional loneliness. A person with deep attachments may lack the connections to make personally important changes. But in combination of its forms, the quantity and quality of social support makes a demonstrable difference to health, to longevity, to the sense of satisfaction with life, and to personal and social power and effectiveness (House, Umberson, & Landis, 1988; Pilisuk & Parks, 1986).

Part of what we know about distinguishing the variety of social supports comes from the different personal consequences of experiencing their absence (Weiss, 1982). When we miss important attachments with intimates, we feel the pain of emotional loneliness . When we lack opportunities for participation with friends, we endure the boredom, aimlessness, and marginality of social isolation. When we are outside a network of personal contacts, we are disadvantaged by insufficient information and limited access to people with resources important to our purposes. Without positive roles in economic and associational life, we have a constrained sense of who we are and diminished power to discover and accomplish what we desire.

Social support counts as much for civic as for personal life. Anastasia Shkilnyk (1985) chronicles the near destruction of a community in her history of the Ojibwa people of Grassy Narrows, Ontario. She describes the vicious circle that begins turning when economic exploitation and physical dislocation combine with inept government assistance policies to break the ties and connections of everyday life. In the resulting vortex of violence, addiction, and cynicism, a people can lose their capacity to raise their children, make their livings, assist their elders, and govern themselves. Less dramatically but as importantly, a growing literature defines the fundamental social importance of altruism —acting with the intention to benefit another person- and the civic challenge of developing ways that people can express their sense of care for one another (Kahn, 1990; Piliavin & Charng, 1990).

Controversies around social support

While almost no one disagrees about the desirability of the actions summed up as social support, citizens should vigorously discuss its implications for public policy. Three characteristics of social support as a concept hinder this necessary debate. Because it is an abstraction which includes a wide variety of everyday behaviors, those who want to talk about social support have a hard time knowing exactly what it means. Indeed, Benjamin Gottlieb (1988) reports that a meeting of researchers on social support, convened by the US National Institute of Mental Health to agree on specific criteria for its definition, only made progress in their discussions when they stopped trying to define social support. Because it is by definition a good thing, those who want to debate social support have trouble raising questions about its limits and problems without sounding sour and cynical. Because it is a technical term, often used as if it described the raw material of professional intervention, citizens may have trouble finding a place in the discussion.

Unless citizens exercise caution, the concept of social support will obscure a necessary fact about the foundations of civil life. We will forget that we are members of each other and that the quality of our lives depends on our remembering this in daily action. To learn more about social support, let particular situations test general claims. This newspaper description of John and Marie's situation opens a window into some important controversies around social support.*

> John, 31, lives with his mother and father and attends a day activity program. He relies on his 73 year old mother, Marie, to assist him with bathing, going to the toilet, and with his meals. She says, *"My other kids have gone off, but because of John, I've never had that empty house feeling_ Between my four kids, I've been taking care of children for 48 years, and the most time I've had off was one week."*
>
> Her fear is that she will die before John is settled in a group home. She says she doesn't expect her other children to look after John, *"Johnny is my problem, and you never really know how your daughter's husband or your son's wife would feel about taking care of him. They'd do it if they had to...But they have their own kids, and they're so busy... A permanent thing wouldn't be fair to them."* [13] (Lewin, 1990)

Should we say that John's mother provides natural support?

Beyond making a home for John and sharing her daily life with him, John's mother, Marie, organizes her day, as she has organized almost half her life time, around the physical work of taking care of him. She also cares about him: she loves her son and feels anxious about his future. This concern leads her to advocate for more group homes and for John's admission to one of them. Policy makers might sweep these different types of caring together under headings like "natural support" or "care by the community" and briefly admire Marie for kindly giving up her time to look after her son. A common, often unspoken, assumption that such caring is a family responsibility and that within the family caring is naturally part of a woman's place makes such a sweeping together easier (Traustadottir,1990; Ungerson, 1987).

The newspaper story reflects this sexist assumption with a twist on the stereotypical portrayal of the silent wife whose picture adds interest to her husband's story. John's father lives with John and Marie and is pictured with them in a large photograph accompanying the article. However, he does not speak in the article, which refers to him only once: *"The specter [of Marie's dying before John moves to a group home] took on new immediacy this month after she passed out briefly in the bathroom and her hus-*

---

* While we have not met John and his family, we discuss their situation because it provides the human dimension in a special report by a major newspaper. We think the writer purposely selected a "good" family –long married parents in their own suburban home with two other grown, successful children– in order to influence public policy by showing the human costs of a scarcity of facilities. The newspaper writer advocates increasing the stock of group homes and assumes that sufficient public funding in a time of deficit is the only point at issue. We will read her account of John's family for what we can learn about social support.

band went to pieces. 'He panics too easily,' she said. 'I'm not sure he could handle Johnny without me.'"

Calling Marie's work social support may be accurate, but misleading. Speaking of Marie's contribution in the same breath as the contribution of a neighbor who might occasionally share an afternoon with John hides a fundamental fact. The whole visible system of residences and day programs for people with mental retardation floats on the invisible work that Marie and tens of thousands of other women do every day. A recent US survey of the need for personal assistance among all people over 15 years of age identifies relatives as providing most of the assistance people require. Relatives are the sole source of assistance for 74% of people who need assistance with personal care, for 71% of people who need assistance with mobility, and for 67% of people who need assistance with household work (World Institute on Disability & Rutgers University Bureau of Economic Research, n.d.). Without Marie's work, unaccounted in cash and thus considered economically unproductive, the service system would face a fiscal crisis that pales its current substantial shortfalls. But because policy makers overlook her contribution, dismissing it as the proper feminine response to a private family trouble, her concerns get left out of decisions about taxation and public spending (Finch, 1989).

Even facts about obvious demographic changes influence policy discussion only marginally. Most everyone knows that a rising proportion of women work outside their homes, and many people know that a growing number of them now provide a substantial part of the practical care and economic support for their elders as well as for their children. Policy makers often rehearse these facts as if to exorcise them by repetition rather than to soberly consider their implications. Citizens can't allow the concept of social support to hide the amount of real work it takes to raise children and honorably assist elders and those of us with disabilities. Instead of allowing professionals to offer answers in the form of confusing generalizations about natural support, citizens should insist on focused discussion of the ways public policy and service practices affect how family members care for one another and how people isolated from family and friends will find informal support (Walker, 1986).

Marie sees two options for John: live with one of her other children or live in a publicly funded residence. She wants to reject the first option as unfair to her non-disabled children and her grandchildren, but fears that the slow pace of growth in residential services may leave her children no choice but to take him in or to place him in an institution (if that is even possible). She notes the irony in the fact that if she had followed professional advice to institutionalize John when he was an infant, he would now have a much better chance to be placed in a group home. By saving the state much of the cost of care for John, she has left the state in a position to ignore him. She does not speak about the possibility that she herself -like many older people- will face institutionalization if she becomes infirm unless her daughter or her daughter-in-law offers substantial practical assistance.

One can understand, though not excuse, policy makers ignoring John and the thousands of other disabled adults now living with their parents. When pressed, responsible officials justify ignoring John with complaints about tight budgets and reference to mixed signals about public willingness to cut other expenditures or pay more taxes so that John has more options. They assign responsibility to shortcomings at other levels of government or to insufficient efforts by charitable organizations. They call these excuses practical realities.

This sense of practical reality includes unquestioned individualism at its foundation. From this perspective, John, whose bad luck with his genetic endowment creates a private problem for his family, has had good luck because his parents have taken care of him and his government offers him a day program. When his family will no longer care for him, his luck will go bad and he will have to accept whatever he gets. As long as his mother continues to look after him uncomplainingly, she is upholding family values. But if she seeks help, especially help at home under her own control, conflict begins. Some policy makers oppose offering more than small amounts of help because they think such intervention erodes what they call family values. Other professional decision makers want to insure that getting help is difficult in order to control what they insensitively call the woodwork effect. (They mean that effective services would draw people in need "out of the woodwork.")

If defining John as the victim of bad luck seems unhelpful, consider the most common alternative explanation. This way of explaining disability assumes that ours is a just world in which people get what they deserve. From this perspective, John or his family somehow deserve visitation with private tragedy in retribution for something they did wrong.

Whether people use misfortune or misconduct to explain John's condition, the implication remains: John's private troubles set him and his family apart from us. We may, if we choose, respond with whatever pity and material charity we can manage. But he and his situation make no moral claim on us. This distance shapes law. No US court has yet held that John has an enforceable right to the service he requires, and even the most progressive legislatures have not gone beyond granting him the privilege of professional screening and placement on a waiting list.

Neither of Marie's apparent options look promising for her and John. Is there another way? Some concerned people combine their frustration at the cold clumsiness of service bureaucracies with their belief in people's willingness to help one another out. They suggest that natural support offers John and his parents -and perhaps overburdened government- a third alternative. Under what conditions could that be true?

If a wider group of people recognized John's membership with them, he would have more people who like and care about him. He would probably have more social resources to draw upon. Presently, his life appears constrained between his membership in his parent's family and clienthood in a day program that walls him off from the ordinary relationships of community life. If one or another of John's personal interests led to his belonging to a community association, he would probably have a more varied and interesting weekly schedule and he might have more allies to work for changes that will benefit him. If John invested some of his energy with members of available social networks, more information and everyday assistance would probably come his way, as it probably would if his family invested energy and made requests on his behalf. If John's neighbors recognized him as belonging among them, he would probably be able to call on a variety of kinds of everyday help and support, especially in clear emergencies which call for straightforward, time limited help. If members of John's extended family accept and enjoy him as a family member, he probably has a claim on a share of whatever resources the rest of the family has. If John had close friends, he would probably have more personal support and encouragement, and, to the extent of his friends' resources, he might be able to draw on more social influence and material goods.

These social resources, available more or less spontaneously and voluntarily once people endorse his membership with them, would greatly improve his possibilities for enjoying a good life. However, three problems cloud John's prospects. The first problem arises from John's current social isolation. The second two problems arise from the social norms that channel the kind and extent of help people will typically offer someone they recognize as belonging to them (Willmott, 1987).

First, though some people do spontaneously reach out to include people whose disabilities significantly inhibit their mobility and communication, moving from isolation to membership typically takes hard work. Very few available services focus on increasing social involvement and most programs actively separate people with walls. Therefore, many of the people with severe disabilities who enjoy membership in community networks and associations do so because their parents -most often their mothers- refused to accept their isolation and worked hard to overcome it. Anyone who would blame John's parents for his isolation and exhort them to work harder to integrate him should contemplate the biblical judgement on those who put together heavy burdens for others to carry (*Matthew, 23,* 2-4).

Second, though some people do spontaneously make heroic efforts for friends and neighbors, John's social world is shaped by rules which express the premise that each person has the individual ability to deal with everyday responsibilities in the long run. Thus, people will offer friends and neighbors and co-workers extraordinary help to see them through a bad time or to aid recovery from a crisis. Those who help may not expect repayment from those they assist, but they typically expect them to recover and get on with their lives in a reasonable period of time. John violates this common expectation of recovery. Even if good instruction and better assistive technology greatly improve his ability to manage his daily routine and contribute productively to economic life, John will most likely need some assistance and guidance and protection throughout the day, everyday, for the rest of his life.

The strength of the expectation that extraordinary help will be somehow time limited shows in the concern and confusion some adoptive families of severely disabled children experience as their children grow up and they confront Marie's dilemma. They entered the adoption freely, and they share their family life generously, but as they realize the lack of acceptable alternative living arrangements they experience anger with the human service system and sometimes resentment of their disabled adult son or daughter for violating the expectation that their family relationship would change as their son or daughter grew up and moved out.

The enduring everydayness of severely disabled people's need for assistance constitutes a strain on them and the people who love them. As Judith Snow (1990), a physically disabled teacher and activist says, *"The hardest part for me is that, no matter what mood I wake up in, the biggest thing on my agenda everyday is to support my attendants and supporters."*

Third, John needs types of assistance which seem unusual to most people because of their intimacy. A friend who accompanies him on an overnight trip will have to deal with helping him use the toilet and take a bath. A co-worker who wants to show him a better way to do his job will have to account for his limited communication and learning skills. A guardian will have to continuously maintain balance between imposing choices on John and seeking and respecting his preferences. None of these kinds of assistance lie beyond most people's competence, and many people who willingly provide them say they are "no big deal." But they lie far enough outside the typical ways that people exchange help to create a barrier. Marie may experience this barrier as a sense that it's too much to ask others to accommodate John's needs. Another person, who might be willing to assist if asked, may be inhibited by discomfort, by a fear of intruding, and by deference to the assumed superiority of those professionals who deal with needs that appear unusual.

It seems reasonable to believe that John could rely on people and associations who know him as a member for many opportunities and for a wide range of kinds of assistance. However, unless people make a conscious and sustained effort to create new ways to organize the expression of their care for one another, the conclusion of Peter Willmott's (1986) review of the literature on available natural support probably holds. He writes, *"families with children or other members [with severe disabilities] may not be socially isolated, but they are likely to lack informal support of a sustained kind from outside the household."* [p.79].

The chances that people outside his family will spontaneously come forward to offer John a lifelong home with them are slim enough to make it unfair to John and his family to build policy on that (implicit) expectation. And it is unjust to leave John no option but to accept others' charity, no matter how generously given, for such fundamentals as his home and a chance to work.

How do human service programs influence the social support John experiences?

If John moves from his parent's home into a professionally directed, government funded group home, he becomes a service client 24 hours of every day. His schedule, his movements, his activities, and his contacts with other people come under the full time scrutiny and control of an interdisciplinary team of human service professionals and their para-professional agents.

What effects can this status have on other citizen's active recognition of his membership in them? On the basis of a national survey of US community residences for people with mental retardation, Bradley Hill and his associates (1984) report that about 8 out of 10 residents have no regular social contact with non-disabled people. In an evaluation of the effects of a national policy aimed at improving community care for people with mental retardation, Gerry Evans and Ann Murcott (1990) show that almost half the people who use services in 4 different Welsh communities have no close friends at all and less than 1 person in 4 has any friend who is not also a client in the same service. In a pointed reflection on his visit to a community group home, McKnight (1989a) says,

> *"...if one would say to the average citizen, 'I want you to take five men and buy a house in a neighborhood in a little town where those five men can live for ten years. And then I want you to be sure that they are unrelated in any significant way to their neighbors, that they will have no friends, and that they will be involved in none of the associational or social life of the town.,' I think that almost every citizen*

> *would say that this is an impossible task.*
> *Nonetheless...systems of ...community services have managed to achieve what most citizens would believe impossible -the isolation of labeled people from community life even though they are embedded in a typical house in a friendly neighborhood in an average town.*"[2]

Some policy analysts see an obvious answer to the isolation and cost created by most current services. Simply combine professionally controlled services (which they often call formal support) with informal or natural support. In this perspective, service workers (often called case managers) make up packages of formal and informal care which match individual needs. Their work will succeed because of their presumed professional skill at assessing and assisting natural supporters. Professionals will multiply the resources available to John while reducing the cash price of his assistance. They will do so by recruiting volunteer companions for isolated people, and by setting up and advising self-help groups, and by organizing the contribution of natural helpers (as professionals have called those people whom others seek out for advice and assistance).

Three problems complicate implementation of this obvious answer. First, something like the informal supports these analysts describe exist all right, but not necessarily in a form that makes them easily identified or coordinated or delivered on schedule in professionally defined doses. What professionals call natural support relationships are necessarily unpredictable. Predictably this stimulates scholarly discussion of how to decide when informal supporters behave inappropriately and what to do about it (Coyne, Wortman, & Lehman, 1988).

Second, many citizens resist attempts to treat them as human service extenders. Co-workers who voluntarily give aid and acceptance to a fellow employee with a disability balk at being seen as part of the person's treatment team, especially when a case manager the co-worker has never met captains the team. Some people professionally identified as part of a person's natural support system say that it is harder to be with a person they care about when they are expected to adopt a professional perspective on their friend.

Third, it is by no means certain that an adequate number of people have time and energy to match the extent of need. As Alan

Walker observes (1982), a government that expects a community to care is guilty of cynicism if it fails to make substantial investments in developing and maintaining an adequate context for caring. In economically developed places, this context includes affordable housing, a fair income, efficient transportation for people who don't have cars, access to decent health care, reasonable child care options, and working conditions that make room for the work of caring and civic participation without exhausting workers. Many Americans live and support one another admirably without these conditions in place. But any weaknesses in the social context decrease the time and energy community members have for John.

If no simple recipe easily blends formal and natural support, does John have an alternative to relying solely on the support of his family, or trusting in the spontaneous support of other community members, or becoming a full time client in isolation? Beyond insuring a social context for mutual caring, can public funds enable ways to combine the resources in John's family and community to support him to live in dignity and safety as a recognized member?

Some thoughtful critics give very long odds on a positive answer to this question. Ivan Illich argues (1976) that increased human ability to analyze life into technically defined problems and hierarchically administered solutions inevitably yields ironic results. With each new possibility for individual expression comes an equal possibility for expanded domination. For example, our desire for medical relief from pain binds us to engineered solutions that erode our ability to care for one another in times of suffering. Healing turns from counsel on living with suffering and dying well to medical control of both the person and a rising share of common wealth in the name of cure. As physicians encounter maladies for which they have no engineered solution, they push for even greater professional control with the result that people's capacity to care and suffer declines even more. This bind generates specifically counterproductive outcomes: more investment in technical solutions creates less health and more impersonal domination of human life.

Extending Illich's analysis to the situation of people with developmental disabilities, John McKnight (1989a, 1989b) identifies a trade off between service and community. The more investment in services, the less community capacity can exist. From this perspective, human service workers steal people with disabilities away from community, and with them the community's capacity for care. Services enrich their workers at the expense of cash income for the people they serve. Service worker's activities systematically dominate and erode ordinary people's capacity to care. Community capacity will flourish when professional dominance is broken and the cash invested directly in services is redistributed to the people who are now clients.

McKnight links his vision of community members with untapped capacity for care to his exposure of professional services as the corrosive agent responsible for isolating disabled people and weakening their fellow citizen's ability to care. His argument deserves questioning. Addiction to inflating assets by manipulating financial instruments rather than by making useful things may be at least as erosive of community as social work is. Elected representatives may not be so easily bamboozled by professional rhetoric as McKnight implies: they may vote appropriations for professional services because they want to exclude and control people whose common membership they deny. And those people who reject disabled people as neighbors and co-workers and schoolmates may not just be victims of professional manipulation or ineptitude. Some of them may indeed fear and blindly despise people they experience as other. But beyond thoughtful debate, McKnight's argument merits testing in action. Can John establish membership in the networks and associations available to his non-disabled brother and sister? How can public resources be redirected in ways that build community settings which include and support John?

A Fertile Dilemma

So John and those who want to help him face a dilemma. Well intentioned efforts to service him are likely to destroy his chances of shared membership and weaken the fabric of ordinary relationships necessary to support every member of his community. But up to now the spontaneous responses of John's community have left him isolated within his family and quite unlikely to find a home and a chance for meaningful activity without organized and (probably) paid for assistance.

This dilemma points to fertile, but stony, ground for people who want to create new social forms. Those people who are potential resources to John need organized ways to recognize his membership with them. They are poorer without him. And John needs reliable assistance that supports his belonging. He is vulnerable without it. How can people committed to recognizing his membership weave a more subtle web with John and his fellow citizens?

A small but growing number of innovators accept this dilemma. Sobered by the possibility that their well intentioned efforts might undermine the community of their desires, and uncertain of who will come forward to recognize and provide daily assistance to people whose membership is in doubt, they work to build new relationships and better forms of assistance. An account of the early news from along several of their paths forms the rest of this paper.

Building community by expanding membership

Three emerging social forms, invented specifically to establish recognition of disabled people as community members, share a common vision and common basic assumptions. Their practitioners work to build communities in which disability does not threaten membership, communities in which disabled people have real opportunities and obligations to discover and contribute their personal gifts. Their practitioners believe:

- ✓ Many if not most people with severe disabilities are vulnerable to exclusion and isolation unless someone makes a focused effort to establish and support their membership
- ✓ Because of the oppression of prejudice and isolation, many severely disabled people and their families face substantial barriers to making connections on their own behalf
- ✓ Many people who are already members of community networks and associations will include people with severe disabilities in their lives and activities given an opportunity to do so
- ✓ Once people who have been separated by apparent disability recognize their common membership, many form mutually satisfying relationships despite apparent differences in ability, appearance, and lifestyle
- ✓ The social fact of exclusion on the basis of disability, routinely expressed in patterns of everyday life and reinforced by most

social policies and service practices, makes it a political act to pursue relationships that contradict exclusion

- ✓ The work of expanding community membership is different from almost every existing form of service to people with disabilities and needs to proceed independent of usual systems
- ✓ Increasing community inclusiveness benefits all people, not just people with disabilities.

These beliefs lead to conscious efforts to redefine the boundaries of shared membership by learning new ways of assisting disabled people to take their place in community.

Each of these three social inventions takes a different path. One builds up community by assisting people to develop personal relationships. Another expands connections to community associations. The third helps people to create circles of support for the expression and pursuit of their dreams.

While each path is distinct, those who successfully practice each form of community building share fundamental approaches to bridging the social distance created by exclusion. They find concrete ways to help people feel their membership in each other by assisting them to identify and act on common interests, to see one another's individuality, and to break the social rules that exclude disabled people (Bogdan & Taylor, 1989; Piliavin & Charng, 1990). They encourage shared activities that will help people become more comfortable with obvious differences (such as staff assigning pointless or infantile tasks as therapy or a person's unusual ways to communicate), deal constructively with practical consequences of disability (such as staff restricting a person from having visitors or a person's use of a wheelchair), and discover mutual satisfactions (such as shared delight in a good meal or pleasure in learning something new). And the paths cross one another. Common membership in a community association can lead to friendship. Members of a support circle may sponsor one another's membership in new associations. A strong and responsible personal relationship may form the nucleus of a support circle.

Michael moved from an institution to a group home and then to a "semi-independent living program," which he quit after meeting and marrying Heather, another person served by a service program. When Michael inherited some money, he agreed to let a local mental retardation agency manage it for him. Rather than protect and invest Michael's inheritance, agency staff spent his funds on everyday expenses in order to impoverish Michael and Heather so they would again qualify for federal income support.

AJ, who works as a citizen advocacy coordinator, agreed with Michael and Heather that he would find someone who would advocate to improve their financial situation. AJ approached Dennis, a prominent local accountant, and invited him to assist Michael.

Dennis voluntarily accepted responsibility to understand and represent Michael's interests as though they were his own. This commitment brought him into an extended conflict when he decided that the agency had irresponsibly mismanaged Michael's funds and should compensate Michael for their poor performance. Ultimately, Michael and Dennis were unsuccessful in recovering any of the mismanaged money. But Dennis did assist Michael to gain control of his remaining money, settle outstanding bills, adjust his lifestyle to live within his diminished income, and reinstate his benefits. He helped Michael find a stronger voice for himself by talking over Michael's options with him and supporting his considered choices. And, when Michael said he didn't want any more of Dennis's help, Dennis withdrew with an understanding that Michael could call on him again for help if he needed it. (Hildebrand, 1991)

Bridget and Harmony are mother and daughter. Two years ago, Harmony received homebound instruction because of her cerebral palsy and multiple hospitalizations for treatment of other neurological problems. Bridget's plans to start a support group for parents of disabled children failed because holding things together for Harmony took all of her available energy. In the process of trying to set up the support group, she met the two citizen advocacy coordinators, who agreed to recruit a citizen advocate for Harmony.

Colleen, who lives nearby, met Bridget and Harmony at the citizen advocacy coordinators' invitation. Colleen spends time with Harmony and enjoys Harmony's company. This not only gives Bridget regular time for other activities, it confirms Bridget's sense of her daughter as a person with important gifts to contribute.

As Colleen came to know and care for Harmony she became aware that Harmony had much to offer other people and decided that Harmony could learn, grow, and contribute in a regular school class. She encouraged and supported Bridget to challenge the professional recommendation that Harmony attend a segregated school in a rehabilitation facility 45 minutes away. Together they persuaded the neighborhood school to accept and provide the necessary support to include Harmony in a regular class, where she and her classmates now do well together (Hildebrand, 1991).

Though they live in the same town and might have passed one another on the street, Michael and Dennis live in different worlds. Though they live close to one another and have children of similar ages, Bridget was so busy taking care of Harmony that she probably would not have had time to meet Colleen. And even if the two women did meet, Bridget might well have felt uncomfortable asking Colleen to regularly take Harmony home with her.

Citizen advocacy coordinators assist those who are unlikely to meet because of the social exclusion of disabled people. They perform effective introductions and offer continued support to personal relationships. They assist freely given relationships: Michael and Harmony are not clients of the citizen advocacy office; Dennis and Colleen are not volunteers to the citizen advocacy office. The citizen advocacy office, which must be independent of the service system, respects and supports the independence of the people in citizen advocacy relationships. A citizen advocacy coordinator focuses single-mindedly on building community by strengthening the bonds of membership between excluded people and ordinary citizens. Their ideal is a community in which more people recognize and act to promote another's human rights, concerns, and interests as if they were their own. Citizen advocacy coordinators want increasing numbers of people to live out one citizen advocate's words, *"I look at him like he was me. I put myself in his shoes, and then I help him out however I can."*

At their best, citizen advocacy relationships form a new kind of social space, a space in which people relieve one another of stereotypes, broaden one another's range of life experiences, and deepen one another's appreciation of what it means to belong. Dennis grew to respect Michael's independence and strength as he learned firsthand of the barriers put in Michael's way by an irresponsible, over controlling agency. Michael grew to respect and trust Dennis because Dennis listened to him first and then offered him practical help based on what Michael said. Colleen and Bridget have come to share a love and concern for Harmony that led them to action which has opened their neighborhood school to children with severe disabilities. Both Dennis and Colleen describe mutual relationships in which they gain (often in unexpected ways) as well as give. Many of the satisfactions of citizen advocacy relationships come from the small pleasures of being together, and getting to know another person, and discovering ways that someone whose life experiences have been very different shares similar feelings and concerns.

People choose a variety of ways to live out citizen advocacy relationships. Sometimes they simply spend time together, sometimes they seek a better response from service agencies, and sometimes they find ways to get what people need outside the service system. Michael and Dennis began their relationship around practical financial problems. They developed a friendly working relationship which expanded as Dennis helped Michael to make better money decisions and to represent his wishes to the operators of the sheltered workshop he attends. Once Michael had the degree of independence he wanted, he stopped regular contact with Dennis. Bridget and Harmony began their relationship with Colleen around Harmony's desire to do things with other people away from home and Bridget's need for some time to herself. From this beginning, they decided to confront their school system's decisions about Harmony. After their success, they continue to support one another day to day.

Like anyone who has an ally, disabled people in citizen advocacy relationships have added strength in dealing with threats and pursuing their interests. And citizen advocates often expand their partner's social network by including the disabled person in their own network of friends and associations. But having an ally, even a strong and loyal ally who shares many resources, doesn't guarantee that situations will come out right. Because of his relationship with Dennis, Michael has more control of his finances, but he has fewer resources because the agency that impoverished him evaded its responsibility to him. Dennis affirms Michael's desire for independence, even though that leads Michael to say no to his offers of further contact and help. The rewards of citizen advocacy relationships come more from a sense of doing the right thing together than from the assurance of good results. One person with a disability summarizes a long effort she and her partner have made to get her a suitable communication device, *"We haven't won yet. They're tough, but we're still trying to educate them. They keep beating us, but we hang in there."*

Andy Baxter (1991) studied the ways effective citizen advocacy coordinators do and think about their work. Beginning from a citizen advocacy coordinator's maxim, *"all we have to work with is questions,"* he highlights the importance of a well focused question to guide the process of introducing people. A good question summarizes what the coordinator knows of the disabled person on whose behalf the coordinator seeks a partner. Powerful questions exactly focus the person's situation in terms clear enough that another citizen can respond with an active yes or a definite no. Much of the citizen advocacy coordinator's art grows from the ability to clearly frame and fearlessly pose such questions. Citizen advocacy coordinators have no recipe and no magic to guarantee a good question, but the search for better questions is at the heart of their work. Well focused questions take shape from intuitions which arise out of careful listening and disciplined thinking.

Sandy is a young woman who has lived briefly in several group homes, but has always been asked to leave after a short time and returned to her parents home. These experiences have left her feeling rejected. She does not work, refuses to attend a day time program, and acts in ways her parents see as irresponsible. Though she says she would like to leave her parents home and live more on her own, she has not been able to do so. Sandy says she would like a citizen advocate to be her friend and help her make it.

Elizabeth, the citizen advocacy coordinator, first considered following this question in her search for a partner for Sandy, *"I am looking for a young woman, who lives nearby and has successfully left home. I will ask this person to be a guide and mentor for Sandy as she pursues her independence."* But this way of framing the question didn't seem quite right. With more thought, Elizabeth saw that Sandy's life had been filled with people unsuccessfully giving guidance and advice and that her response to them was closely followed by their rejection of her. So the citizen advocacy coordinator's question shifted: *"I am asking you to try to build a relationship with Sandy, in the hope that the two of you will come to like each other very much, and in the hope that yours will become a lasting, close friendship. Out of your friendship, gentle guidance can emerge, and you may not even realize that you are guiding your friend. Can you picture yourself as a person who can make a long, close, and faithful commitment to another person?"* Based on this question, Elizabeth found Sandy a partner. [22] (Baxter, 1991)

Of course it will be up to Sandy and her partner to decide how their relationship goes. People give their relationships direction, shape, and texture as they respond to one another and to outside events over time. But the way citizen advocacy coordinators go about introducing people and supporting relationships makes an important difference to the quality of most relationships.

By introducing people one to another, citizen advocacy programs remind people of their shared membership in one another. By supporting relationships as they evolve, citizen advocacy programs strengthen people's ability to act responsibly toward one another.

Connecting People to Community Associations

Since her mother's death, Betty, who is in her 60's, had almost no contact with anyone outside the group home she lives in.

Then Betty met Kathy, who works on a community building project sponsored by the local neighborhood organization. From spending time with Betty, Kathy learned that Betty wanted to go to church, something she had enjoyed with her mother but lacked the opportunity to do.

Kathy asked Mary, a leader in the neighborhood association and a long time member of the Church of the Advent, to sponsor Betty's church membership. This means taking Betty to church every Sunday, sitting with her, and making sure she has opportunities to participate in the life of the congregation after formal services. Sometimes Mary, or someone else who knows Betty well, needs to "translate" for those church members who have difficulty understanding Betty.

Before the first Sunday, Mary was unsure that she would know what to do to assist Betty and uncertain whether she could spare the time to help Betty get to church. But her feelings changed, *"Once I met Betty, there was no way I could not take her to church. Betty's a neat person... she is enthusiastic and has a sense of humor. You don't have to put on any pretensions around her."* [1]

Betty participates actively in services and particularly enjoys exchanging the greeting of peace with the rector and other members of the congregation. During the bishop's visitation, he processed through the church, blessing the people in each pew. When he blessed Mary and her family, Betty enthusiastically waved back to him. After the service, the bishop took time to meet Betty and spend a moment with her.

Betty saves each week's church bulletin. The bulletins are one small sign of her membership. They signify the only place where Betty belongs and is not one of a group of elderly, severely retarded clients. (LeWare, 1989)

As part of her job, Sharon developed community living arrangements in a small town for 8 people who had previously lived in nursing homes. As time went by, the pride she shared in their new homes turned into concern for their isolation. Her concern became confusion as she recognized that neither she nor her staff knew much about the life of the town and how to help outsiders become part of it.

Sharon enlisted Francis to act as a "bridge builder." Francis is a long-time leader of local associations from the town's marching band to a food pantry for the town's many unemployed industrial workers, She asked him, as an expert in community life, to introduce previously excluded people to community associations that will benefit from their contribution.

Francis introduced Arthur, a man who spent over 50 years in institutions, to membership in the core group of volunteers who operate the community food pantry. For more than 2 years, Arthur has greeted people as they arrive and handed them the numbers that tell them when it's their turn to be served. Though it can take Arthur a long time to complete a statement, his co-workers and a number of the people who come to the pantry say they enjoy talking to him.

Arthur's strong desire to help others forms the foundation of his membership. Because of their common desire, the other volunteers have overcome problems that some professionals identify as significant barriers to Arthur's community involvement. The other members of the core group have dealt with Arthur's inability to keep the number tags straight by teaching him to recognize more numbers and by helping him arrange the tags in order on a stick. The group's leader deals firmly with the few customers who occasionally complain about Arthur's presence. Rather than trying to correct him, the people at the food pantry have redefined his "institutional behavior" of securing possessions –such as his Food Pantry name tag– by wrapping them in multiple layers of handkerchiefs, old socks, and bags. His colleagues consider this habit Arthur's way of showing how much he prizes his name tag and how proud he is to belong with them. (Gretz, 1988).

Kathy and Sharon assisted Betty and Arthur to new roles in their community because they know their community differently than the residential and day staff who serve Betty and Arthur do. The staff see community as the location of their jobs, as the address of the buildings in which they provide residential and day activity services. For the staff, community includes places that staff might take Betty and Arthur if sufficient staff hours remain after providing state required treatments, and if the van is available, and if they are certain that Betty and Arthur have the skills to handle the requirements of the setting. Kathy and Sharon see community as a medium in which people join together to grow diverse associations. They are inspired by the late 20th century possibilities raised by Alexis de Tocqueville's (1990) observation on the distinctive character of early 19th century America.

> *Americans of all ages, all conditions, and all dispositions constantly form associations. They have not only commercial and manufacturing companies, ... but associations of a thousand other kinds, religious, moral, serious, futile, general or restricted, enormous or diminutive.* [vol 2, p. 106]

So Kathy and Sharon see the congregation of the Church of the Advent and the core group of the community food pantry. And they see Mary and Francis as able to welcome Betty and Arthur as members because Mary and Francis are already active members with a great potential to extend hospitality.

Arising along with their distinct perspective on community, Kathy and Sharon know Betty and Arthur in a different way than residential and day services staff do. Both Betty and Arthur are older and have numerous apparent disabilities. Because they have had limited success in remediation activities, staff see Betty and Arthur in terms of their deficits. Staff interpret Betty's and Arthur's disabilities as generalized limitations on the possibility that local people can accept them, except as full time service clients. Kathy and Sharon search for the personal interests and capacities that will connect Betty and Arthur to the associational life of their communities. John McKnight (1987) expresses the foundation for their confidence that Betty and Arthur belong, *"...community structures tend to proliferate until they create a place for everyone, no matter how fallible."* [p. 3]

For Kathy and Sharon, Betty and Arthur are not the problem. For them, the problem is Betty's and Arthur's disconnection from local associations. Kathy discovered the extent of this disconnection as she explored her neighborhood's associational life by interviewing over 100 of its leaders. Among these, the most active people in the neighborhood, only a few reported any contact at all with a severely disabled person, and none knew someone with a disability personally (O'Connell, 1990). These people, and the associations they lead, represent an untapped resource for people with severe disabilities. And people with severe disabilities can contribute new energy, new abilities, and new meaning to the associations that enliven the communities they live in. Kathy and Sharon choose to organize their work around discovering which of the many forms of local associational life suits Betty and Arthur and assisting them to join. They work through trust and time.

To discover opportunities, Kathy and Sharon identify community leaders, like Mary and Francis, and enlist their interest by appealing to the common value people place on hospitality. Thus, on behalf of outsiders, they gain an insider's knowledge of and access to a community's people and their associations. Francis sums up the art of involving people like this, *"To get people involved, you first have to let them know that they have something valuable to offer. Than you ask them. Period."*(Gretz, 1991) Kathy and Sharon spend enough time with Betty and Arthur to appreciate them as individuals and to learn something of their gifts. Sometimes a person's interests are obvious. Arthur frequently says he wants to help people who are down on their luck. In this desire, Sharon can see a link between Arthur and Francis. Watching Betty pantomime kneeling and praying in church when asked what she likes to do leads Kathy to remember Mary's active role in her congregation. Sometimes, gifts are hidden and can only be discovered by people willing to thoughtfully share new experiences with a person.

To assist them to join an association that matches their interests, Kathy and Sharon encourage the association's members to reach out and include Betty and Arthur. Kathy and Sharon don't pose as disability inclusion experts, ready to solve every problem. They trust people's ability to find solutions for themselves once they recognize someone as a member. An association's capacity to create a place is especially strong when a well established member acts as the newcomer's sponsor, as Mary does for Betty and Francis does for Arthur. This trust in association members doesn't come easy. Sharon says,

> *...after Arthur had been at the pantry several months, Francis called me to say... that Arthur wasn't making it to the bathroom on time and was wetting himself. My reaction was one of horror and fear; fear that they were going to suggest he not come any more. Sure that I was going to beat Francis to the punch, I suggested perhaps someone else [from the residential program] could take Arthur's place.*
>
> *Francis was shocked. "Absolutely not!" he replied. Arthur belonged with them. They just wanted to solve the problem.* (Gretz, 1991)

Kathy and Sharon recognize that membership in a community association can bring new parts of a person to life. Arthur grows as his desire to help others finds an outlet that offers him responsibilities, challenges, and rewards. And they know that including someone previously outside the circle of membership can renew an association. Some members of Betty's congregation feel that her spontaneous responses –like hugging the people she knows best when it is time for the greeting of peace– bring their rituals back to their roots.

Bringing excluded people into membership satisfies and energizes their hosts, but not everyone extends a welcome. Mary O'Connell (1990) identifies four difficulties, rooted in people's lack of experience, that limit association member's readiness to include people with disabilities.

- ✗ Some people feel too busy to make time for a person who could require some extra assistance. Most active citizens balance work, family obligations, personal interests, and association duties and they may see including a person with a severe disability as a time consuming activity.
- ✗ People with severe disabilities raise some people's uncertainties about their competence to respond properly,the extent and limits of their responsibility, and their ability to deal with other's reactions to someone they assume is different. They don't see a disabled person as a potential contributor but as a kind of a project.
- ✗ Some association leaders think of involving people with severe disabilities as a kind of extra activity which competes with the group's mission and perhaps exposes the association to new liabilities.
- ✗ Some people plainly reject others with severe disabilities. And service providers often aggravate citizen concerns when they make it clear that they believe that "special" activities are better and that they ultimately control their clients' time.

New memberships significantly expand Betty's and Arthur's social worlds, but both people still spend most of their time as clients of human services because by nature the associations that welcome them don't offer more than part time involvement to any of their members. Their fellow members welcome them and accommodate their individual differences in the context of the church or the food pantry, and their membership may spill over into new acquaintances as growing numbers of people talk with Betty in the coffee hour after church or greet Arthur on the street. However, current service arrangements make their memberships fragile. The professional team that controls Betty's life could decide that she should move to a group home in another neighborhood. Direct service staff could discourage Arthur from spending time at the food pantry because it is too much bother for them to help him get ready. No doubt Mary and Francis would fight for Betty and Arthur's continuing membership, but the service programs retain power as long as Betty and Arthur remain tied to them by the lack of alternative sources of personal assistance. For now, Betty and Arthur's freedom of association depends on the value their service providers decide to place on their membership.

Kathy works in an inner city Chicago neighborhood. Sharon works in a small town hard hit by recession. Some people might doubt that either locality would have vital associations willing to welcome outsiders with severe disabilities. But, though troubled, both communities remain alive because some citizens invest their energy in building and sustaining associations. To find the associations that match the individual interests of people with severe disabilities requires that someone carefully follow leads from one person to the next in order to identify opportunities and sponsors. Both communities have associational leaders like Mary and Francis who will recognize and welcome the contribution of people with severe disabilities. To enlist them requires that someone earn their trust through an honest appeal to their sense of hospitality and a continuing willingness help with problem solving.

Kathy and Sharon confirm the importance of associations in community life by working to increase the diversity of people that association members recognize as belonging among their number. By so doing they strengthen their communities as they open new opportunities for people with severe disabilities.

At 17, Kevin attended a segregated, hospital-based school for people with multiple handicaps. Because his teachers believed that he could not benefit from academic instruction, Kevin's educational program included physical therapy, music therapy, group therapy, and basic skills like shape and color identification, sorting, and collating. Because students in his class were collected from a large area, and because he went to school a long way from home, Kevin made few after school friendships. Despite his energy, his sense of humor, and his interests in sports, computers, and socializing, Kevin was isolated. Most of his contact was with his brother Jason, his mother, Linda, and his father, Carl.

Linda's concern for her son's future led her family into participation in a project aimed at developing circles of support. With the help of facilitators employed by the project, Linda invited two close friends and their teenagers and Tracy, a senior at the local high school who knew Kevin from summer camp, to meet in her home with her family. As the circle shared their appreciation of Kevin's capacities and ideas about his future, Jason challenged the circle to work for Kevin's inclusion in the local high school.

Kevin enthusiastically agreed, and the circle began several months of planning, problem solving, and advocacy with the school system. Some adult resource people joined the circle to help negotiate system problems. Some more students joined to help Kevin develop a schedule of classes and activities that matched his interests.

At 19, Kevin is a high school senior who particularly enjoys computer lab, art, history, and social science classes (where he completed a project on "Cerebral Palsy and the Brain"). In addition to attending school sports events, and social activities like the Prom, Kevin belongs to the Peer Leadership Club and the Future Business Leaders of America. His ability with the computer his circle helped him get has led him to join the local MacUsers group and his interest in graphic arts brought him membership in a local association of artists.

Kevin's circle continues to help him focus and work toward his vision of life after graduation. (Meadows, 1991)

Six years after graduating from college, Cathy was working part time as a writer and editor, and living with her mother, who provided most of the personal assistance she needed. Cathy says,*"an incredible sort of numb despair settled over my life"* as she grappled with the barriers that surrounded her. She was unable to find a new living arrangement offering her the amount of attendant service she needs and couldn't break out of the benefits trap that keeps her from earning a fair wage. She stopped thinking about her future: *"I would continue to live with my mother, working where and when I could, and when she could no longer get me up and dressed and out of bed, I would go and live in a nursing home. I didn't like it, but I could see no other way."* [1988, p.6]

Then Cathy saw a way to live *"free and safe."* In a workshop sponsored by a project exploring circles of support, she learned about cooperative housing associations and an approach to consumer controlled attendant services that could provide the assistance she needs to deal with her serious and continual breathing problems. She also got help in organizing her mother and 7 of her friends into a support circle.

Cathy's circle offers her encouragement, creative ideas, contacts, companionship, and practical help as she pursues her dream of a housing co-op. As she has worked over the past 3 years to make her dream real, the circle has grown to include a property developer and an expert on cooperatives. She and her circle have joined other activists to analyze and lobby for change in the policies that block decent housing and effective attendant services.

As she has pursued her big dream, Cathy has learned to realize smaller ones. With the support of her circle she has become more confident in hiring her own personal care assistants and more willing to travel and pursue new experiences. (Ludlum, 1991; 1988).

Kevin and Cathy and their circles of support demonstrate the possibilities of conscious interdependence. Before their circles formed, both lived as valued members of their families and both were service clients. However, without their circles, neither had the support to bring a vision of a desirable personal future into clear focus and neither had the social resources to work toward significant change in the way human services treat them.

Circles of support organize around dreams that have gone unheard, even by the person at the center of the circle. These dreams direct action because they communicate a person's unique capacities and gifts and thus define the sort of opportunities necessary for personal and community growth (Snow, 1991). Such organizing dreams take shape and gather force when people show their appreciation for another's gifts by listening carefully, affirming the dream by taking some action, waiting for the person's dream to clarify and deepen in response to affirmation, and challenging the person and other members of the circle to be faithful to the dream (Pearpoint, 1990). The dreams that focus circles are not arcane. Cathy's dream of a congenial housing cooperative doesn't require interpretation by a qualified analyst. It straightforwardly calls for her and members of her circle to do some hard work. Dreams are not blueprints. Kevin's dream of using his interest in computer graphics to make a living points a direction that will grow more clear as he tries things and discovers what works for him.

People with very little ability to communicate, people with limited experience, and people who have been oppressed into internal silence rely on others to begin to articulate a dream for them. Kevin's brother, Jason, challenges his family and friends with a vision of Kevin joining him at school. Kevin's enthusiasm and the energy this dream generates in the rest of the circle confirms Jason's dream for Kevin. Dreaming for another is, of course, dangerous: a vulnerable person could easily get trapped in what someone else thinks should be good for them. Dreaming for another must arise from a kind of love that includes recognition of the other person's separate identity. It is a dialogue of action in which circle members take a step and then carefully wait to see whether the person they are concerned for responds with a next step that confirms or redirects them.

Typical human service practice doesn't respond to people's dreams and support their capacities. It takes shape around professional accounts of people's deficiencies and policies designed to ration public funds. Kevin was excluded from opportunities to make friends and learn history by receiving the measure of service professionally judged to match his level of disability. Cathy couldn't set up her own home because service system policies deny her the number of hours of attendant services she requires. Kevin and Cathy were not excluded by accident or professional incompetence but by design and by professionals doing their jobs according to accepted practice. A circle that shrinks from confronting the injustice taken for granted in the lives of people with severe disabilities will quickly lose energy and direction. Action to follow Kevin and Cathy's dreams includes renegotiating the terms on which they get the assistance they need and redesigning policies that disadvantage them. Kevin's circle found a way around his school district's special education practice which allows him to be in school and to combine the extra help he needs in some areas with opportunities to enjoy the resources of regular teachers, students, and school activities. Cathy's circle searches for ways to provide her home through action outside disability services and the assistance she needs through changed policies. Changes for Kevin and Cathy set new precedents and help make policy changes that other people with severe disabilities can benefit from.

Circles of support are explicitly constructed with the specific intention of assisting the person at their center. Circle members gather regularly for meetings. Facilitators play an important role in helping a person organize a circle, guiding circle members in discovering the focus person's dream and making personal commitments to take action to help the focus person realize the dream, and supporting the continuous process of problem solving that structures the circle's work. Experienced facilitators have written guidelines and advice and developed facilitator training programs (Beeman, Ducharme, & Mount, 1989; Snow, 1989).

Invited people from Kevin's and Cathy's social networks commit themselves to form the support circles. Some people with limited contacts or ability to communicate rely on a close ally to extend the invitation, and many of the most powerful circles form around a strong one-to-one relationship (Snow, 1989). With the guidance of facilitators, Linda invited some of her friends and one of Kevin's contacts to join her family to clarify their collective sense of Kevin's future. Others make their own invitations. With the guidance of facilitators, Cathy invited her friends and her mother to join her in figuring out how to make her vision of a better life.

As the circle's work proceeds, its size and composition often changes. Members reach out through their own social networks to include others with needed talents. Some people leave the circle as the time for their contribution passes or their available energy decreases. When a circle forms around a child, facilitators often support the development of two somewhat interlocked circles: one circle of young people, usually focused on the school and social life of the child, and another circle focused on the parents (Snow & Forest, 1988).

Some circles develop a shifting focus: the person for whom the circle convened sometimes moves out of the center of the circle's concern and another circle member's needs take precedence for a time. Cathy particularly enjoys the fact that others can benefit from the focused energy of the circle she has organized.

Circles are contagious. Once some people have experienced their power they want to share it. One of the members of Cathy's circle formed a circle for herself, and several other people involved in circles formed by the project that supports Kevin and Cathy have learned to facilitate circles for other people.

Reflecting on her experience with support circles, Beth Mount (1991) identifies some conditions associated with significant change. These conditions describe a support circle with a good chance of making a positive difference in the quality of a person's life.

- ☐ The focus person wants a change and agrees to work with a circle of support; support circles can't be forced on people
- ☐ All of the circle members, including the focus person, attend to the person's capacities and gifts and search for opportunities rather than dwelling on disabilities, deficiencies, and barriers.
- ☐ Circle members have chances to find out about new possibilities and new ways to organize the assistance the focus person needs
- ☐ The circle shares a clear vision of a different life for the focus person, and the vision vividly defines the kind of opportunities the focus person needs to share unique gifts and pursue individual interests
- ☐ At least one circle member has a strong commitment to act vigorously on the focus person's behalf. 6) At least one circle member has a broad network of contacts in the focus person's local community and the skill and desire to help the focus person build ties to other people
- ☐ A skilled facilitator is available to the support circle
- ☐ Some support circle members are active in organizations and coalitions aimed at changing unjust or ineffective policies
- ☐ Some circle members develop influence with the people who make policy and administer human service programs that affect the quality of the focus person's life

☐ At least one human service program the focus person relies on has an explicit commitment to continuous improvement in its ability to support people's full participation in community life.

The stringency of these conditions is a measure of the distance between everyday life for people with severe disabilities and simple dreams like having friends, a job, and a home of one's own.

Circles of support offer people a structure for discovering and celebrating their membership in one another. By working together with someone who would be unable to realize an important dream without their support, circle members remember the human interdependencies which form the foundation of civic life.

How human services could help

Working outside the human service system, and frequently against opposition from service professionals, some citizens accomplish a great deal for the people they know and care for. Many parents have raised their severely disabled children as full participants in family and community life with little or no help from service programs (Schaefer, 1982). Citizen advocates have taken institutionalized children into their homes without professional sanction or support and helped families adapt or even build homes that allow them to better look after a severely disabled member (Bogdan, 1987). Circles of fellow students welcome, support, and protect severely disabled classmates in schools across North America (Perske, 1988).

However, it is unjust to expect that opportunities for people with severe disabilities should depend on heroic efforts to outwit segregating policies and work around misdirected professional practice. Human service programs can't substitute for freely given relationships; indeed, service programs destroy people's membership in community when they try to replace ordinary activities and relationships. But human services don't have to be the major obstacle to people's pursuit of their dreams.

Simple changes in common practice would create more room for relationships and memberships to form and grow. Service staff could reduce barriers...

...if they stopped acting as if they owned the people they serve and could arbitrarily terminate their contacts or disrupt their memberships

... if they modified schedules and tasks to accommodate people's relationships and memberships

... if they recognized and encouraged activities and contacts outside their programs

...if they looked for the flexibility to assist with some of the ideas and plans that emerge from new relationships and new memberships

These changes in attitude and practice would help some, but the work of community builders suggests important policy changes that add up to a system better able to assist people without destroying their sense of community membership.

Members of 12 different support circles in Connecticut developed thoughtful analyses of the human service policies that block opportunities for personal and family development, for good schooling, for employment, and for secure homes. They discussed the problems they identify and their proposed solutions in a series of policy forums that included political and administrative decision makers. Policy makers and administrators who want to be of genuine assistance, would follow these six directions:

- ✓ Increase the amount of personal assistance (attendant and family support) services available to people based on individual need by reallocating all funds that now support various forms of congregate long term care. Make personal assistance services more flexible by putting them under the direct control of the person who uses them, or, if the person is a child, under control of the child's family. Demedicalize personal assistance services.
- ✓ Insure that people with severe disabilities have an adequate cash income and adequate health insurance. Eliminate benefits traps that prevent people who want to work from doing so. Eliminate stigmatizing practices.
- ✓ Support individual or cooperative home ownership for adults with severe disabilities. Break programmatic links that tie people who need a particular type or amount of support to an agency owned building.
- ✓ Offer a wide variety of supports for individual employment in good jobs of people's choice.
- ✓ Insure that local schools fully include students with severe disabilities.

✓ Invest in safe and accessible transportation.

Within these policies, human service programs have a reasonable chance to develop the competencies necessary to assist people to pursue their own lives while maintaining community membership (Ferguson, Hibbard, Leinen, & Schaff, 1990).

Paradoxes of Community Building

The work of building communities in which people with severe disabilities are recognized members requires a talent for finding the truth in apparent contradictions. So far as community building has developed to date, paradox shapes the requirements of the work, and no one who insists on simple, unambiguous instructions can understand the work or do it well.

Each form of community building that we have described celebrates freely given contributions, but the people who invite and support these unpaid relationships are either paid to do so or earn their living in a way that lets them devote substantial time to this work. Overcoming the social forces that push and pull people with severe disabilities out of community requires hard, sustained work. It takes time to get to know people; it takes time to listen for people's interests; it takes time to seek out new opportunities; it takes time to make introductions; it takes time to give people the assistance they want with problem solving. Many of the people who freely offer the gift of hospitality and bring people into membership recognize an essential and usually continuing contribution from community building project staff (the citizen advocacy coordinator, the person paid to link people to associations, and the circle facilitator).

Community building staff frequently distance themselves from human service program staff, but they are themselves paid for their work with disabled people, most frequently out of grant funds earmarked for human services. Though it is clear that the work of community building can be destroyed when it is mixed up with the work of typical human service programs, its proper home and proper sources of funding are far from clear. Community building staff identify themselves with communities and their associations; but many community association leaders see and respect them as workers for disabled people. Community building staff speak eloquently of the benefits of inclusive community for all people, but many active citizens speak of themselves as finding satisfaction in helping the disabled.

Each form of community building celebrates the wisdom and ability of ordinary citizens, but many ordinary citizens have so much difficulty recognizing their common membership with a severely disabled person that they need someone they recognize as an expert to ratify their competence. Many ordinary citizens feel uncomfortable in the world of disability services and need someone to tell them that their perceptions of people and situations and their ideas for action make sense even if they disagree with the psychologist; even if they don't understand the acronyms; even if they can't cite pertinent case law. Many people who have worked skillfully and faithfully to assist a person with a disability to overcome serious problems talk appreciatively of community building project staff as disability experts, however uncomfortable that may make the staff.

Practitioners of each form of community building celebrate actions that rescue people from the human service system and return them to the natural support of their community, but most of the severely disabled people now involved in community building efforts still rely substantially on human services, and many are almost totally controlled by service practices despite the committed involvement of ordinary citizens. Despite bureaucratic dreams of smooth coordination between service providers and advocates for individuals, the relationship between service providers and the people they serve remains fundamentally problematical. No system can be trusted to always know and pursue the best interests of each person. Every system balances support for individuals with the tasks of social control. Any system can slip into tyranny and abuse. So community building efforts won't succeed by ignoring basic conflicts of interest between severely disabled people and human service systems. But if it is hard for people with severe disabilities to live with flawed human service programs, it is harder for most to live without them. Citizen advocates, fellow association members, and circle members make a priceless contribution to people's well being; but very few of them have the social resources to sustain the people they care about completely outside the human service system. To act wisely, they need to recognize the inherent limits of service programs but then to identify and then to insist on the contributions that service programs can make to disabled people's well being. Those who ignore or belittle political action on an agenda like the one pursued by Connecticut's allied circle members, greatly reduce the possibility that severely disabled people will have the assistance they need to enjoy the opportunities that new memberships and new relationships open up to them.

Many people consider spontaneity the hallmark of personal relationships. Most everyone today would be uncomfortable with the idea of outsiders manufacturing and managing personal relationships, but community building efforts always involve carefully planned introductions which are usually followed with well organized efforts to resolve problems and pursue opportunities. It takes little more than a welcome to achieve a persons presence in an activity or an association. Becoming a full and valued participant takes conscious effort. Of course, work on a friendship or on inducting someone into full membership happens commonly, but this is usually the exclusive business of insiders. A third party (like a citizen advocacy coordinator, or a person whose job is helping associations to include people with disabilities, or a circle facilitator) seldom influences or orchestrates ordinary relationships and memberships. Some people reject any suggestion of systematic work to make and expand a valued place for someone who has been excluded because they feel that such efforts would be contrived or artificial. Yet without such work, many people with disabilities fall back into isolation.

These paradoxes define some of the most important issues for the future of explicit efforts to bring people from moral and social exclusion to membership. People concerned to build communities need to keep learning how to deal constructively with...

☐ Being paid supporters of voluntary efforts

☐ Being seen by many community members as somehow part of a system whose hold on people they, as community builders, are committed to undo

☐ Acting as disability experts whose message is that most disability specific expertise has little relevance

☐ Developing as many opportunities as possible outside the jurisdiction of a system of human service programs that virtually all people with severe disabilities will continue to depend upon

☐ Offering necessary structures to invite people to spontaneously develop positive relationships and satisfying associations.

Conclusion

Clear recognition of shared membership offers people a place in the web of friendships, exchange networks, and associations that support life. But many community members leave out people with severe disabilities when they count the people who belong with them in their neighborhoods, schools, work places, and cultural, political, and leisure activities. This unfortunate exclusion decreases the human diversity that can energize civic life, with obvious cost to people with severe disabilities and their families.

Given the opportunity to meet people with severe disabilities and share their lives and their dreams, many people overcome the pressures that deny their membership. Social innovators have created several ways to help people build positive relationships, increase the diversity of association membership, and take joint action to make positive changes.

Inclusion among the recognized members of a community cannot substitute for public investment in a variety of supports and opportunities for people with substantial, continuing need for assistance. Social support is not a substitute for well designed services; social support is the foundation for any effective service. Conflict involving excluded people will always be harder to resolve justly than conflict among members. Excluded people will always be more difficult to assist effectively than people whose common membership is recognized by all and celebrated by some.

Civic life depends on citizens' willingness to recognize and support one another's membership despite apparent differences. All people will live better lives when the knowledge that we are all members of each other shapes everyday life and collective decisions.

References

For more information about citizen advocacy, contact: Georgia Advocacy Office, 1708 Peachtree St., Suite 505, Atlanta, GA 30309

For more information about assisting people to become members of community associations, contact: Kathy Bartholomew-Lorimer, Center for Urban Affairs 2040 Sheridan Rd. Evanston, IL 60208 and Association Integration Project, 56 Suffolk St, Suite 500 Holyoke, MA 01040

For more information about circles of support, contact: Centre for Integrated Education and Community, 24 Thome Crescent, Toronto, ON M6H 2S5 and Communitas P.O. Box 374 Manchester, CT 06040

Baxter, A. (1991). *How citizen advocacy coordinators do their work*. Atlanta, GA: Georgia Advocacy Office.

Beeman, P., Ducharme, G., & Mount, B. (1989). *One candle power: Building bridges into community life with people with disabilities.* Manchester, CT: Communitas.

Berry, W. (1986). *The wild birds: Six stories of the Port William membership.* San Francisco: North Point Press.

Bogdan, R. (1987).*We take care of our own: Georgia Citizen Advocacy in Savannah and Macon.* Syracuse, NY: Center on Human Policy.

Bogdan, R. & Taylor, S. (1989). Relationships with severely disabled people: The social construction of humanness. *Social Problems, 36*, 2, 135- 148.

Bulmer, M. (1987). *The social basis of community care*. London: Allen & Unwin.

Coyne, J., Wortman, C., & Lehman, D. The other side of support: Emotional overinvolvement and miscarried helping. In B. Gottlieb (Ed.), *Marshaling social support: Formats, processes, and effects* (pp. 11-51). Newbury Park, CA: Sage Publications.

Edwards, J. & Dawson, D. (1983). *My friend David: A source book about Down's syndrome and a personal story about friendship*. Portland, OR:Ednick.

Evans, G. & Murcott, A. (1990) Community care: Relationships and control. *Disability, Handicap & Society, 5*, 2, 123-135.

Ferguson, P., Hibbard, M., Leinen, J. & Schaff, S. (1990). Supported community life: Disability policy and the renewal of mediating structures. *Journal of Disability Policy Studies, 1*, 1: 10-35.

Flynn, M. (1989). *Independent living for adults with mental handicap: A place of my own*. London: Cassell Educational Ltd.

Finch, J. (1989). Social policy, social engineering, and the family in the 1990s. In M. Bulmer, J. Lewis, & D. Piachaud (Eds.), *The goals of social policy*. London: Unwin Hyman.

Gallagher, H. (1989). Evolving medical attitudes toward the quality of life. In B. Duncan & D. Woods (Eds.), *Ethical issues in disability and rehabilitation* (pp. 17-25). New York: World Rehabilitation Fund.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.

Gottlieb, B. (1988), Marshaling social support: The state of the art in research and practice. In B. Gottlieb (Ed.), *Marshaling social support: Formats, processes, and effects*, pp. 11-51. Newbury Park, CA: Sage Publications.

Gretz, S. (1991). Citizen participation: Connecting people to associational life. In D. Schwartz, *The other side of the river: The conceptual/social revolution in developmental disabilities.* Cambridge, MA: Brookline.

Gretz, S. (1988, September). About being a citizen. *The Developmental Disabilities Planner, 5*, 2, p 1, 4.

Hagner, D. (1989). *The social integration of supported employees: A qualitative study.* Syracuse, NY: Center on Human Policy

Hildebrand, A. (1991). Asking for citizen advocates in Beaver County. In D. Schwartz, *The other side of the river: The conceptual/social revolution in developmental disabilities.* Cambridge, MA: Brookline.

Hill, B., Rotegard, L., & Bruininks, R. Quality of life of mentally retarded people in residential care. *Social Work, 29*, 275-281.

House, J., Umberson, D. & Landis, K. (1988). Structures and processes of social support, *Annual Review of Sociology*, 14: 293-318.

Illich, I. (1976). *Medical nemesis: The expropriation of health.* NY: Pantheon.

Kallenback, D. & Lyons, A. (1989). *Government spending for the poor in Cook County, Illinois: Can we do better?* Evanston, IL: Center for Urban Affairs and Policy research, Northwestern University.

LaFrancis, M. (1990). *Welcoming newcomers to community groups.* Holyoke, MA: Education for Community Initiatives.

Leatham, G. & Duck, S, (1990). Conversations with friends and the dynamics of social support. In S. Duck (Ed.) *Personal relationships and social support* (pp. 1-29). Newbury Park, CA: Sage Publications.

LeWare, M. (1989). Community opens it's church doors for Betty. *Building bridges: Stories about community building in Logan Square.* 1: 1, pp. 1-2.

Lewin, T. (1990, 28 October). When the retarded grow old: A special report. *The New York Times*, pp. 1, 13.

Lord, J. & Pedlar, A. (1990). *Life in the community: Four years after the close of an institution.* Kitchner, ON: Centre for Research & Education in Human Services.

Ludlum, C. (1991). The power of a circle of support. In B. Mount, *Dare to dream: An analysis of the conditions leading to personal change for people with disabilities.* Manchester, CT: Communitas.

Ludlum, C. (1988). My circle. In B. Mount, P. Beeman, & G. Ducharme, *What are we learning about circles of support?* Manchester, CT: Communitas.

Lutfiyya, Z. (1990). *Affectionate bonds: What we can learn by listening to friends.* Syracuse, NY: Center on Human Policy.

McKnight, J. (1989a). *Beyond community services.* Center for Urban Affairs Paper. Evanston, IL: Northwestern University.

McKnight, J. (1989b). *First do no harm.* Center for Urban Affairs Paper. Evanston, IL: Northwestern University.

McKnight, J. (1987). Regenerating community. *Social Policy, 17*, (3), 54-58.

Martinez, C. (1988, April). *Quality of life.* Presentation to the US Commission on Civil Rights Conference on Quality of Life. Washington, DC.

Meadows, L. (1991), Kevin's story: Focus on capacity. In B. Mount, *Dare to dream: An analysis of the conditions leading to personal change for people with disabilities.* Manchester, CT: Communitas.

Melberg-Schwier, K. (1990). *Speakeasy: People with mental handicaps talk about their lives in institutions and in the community.* Austin, TX: Pro-Ed.

O'Brien, J. (1988). Field notes from the Connecticut DMR Family Support Program evaluation.

O'Connell, M. (1990). *Community building in Logan Square: How a community grew stronger with the contributions of people with disabilities.* Evanston, IL: Northwestern University Center for Urban Affairs & Policy Research.

Opotow, S. (1990). Moral exclusion and injustice [Special issue]. *Journal of Social Issues, 46*, 1.

Osburn, J. (1988). *Welcome to the club: Report of an external evaluation of the Association Integration Project.* Holyoke,MA: Education for Community Initiatives.

Pearpoint, J. (1990). *From behind the piano: The building of Judith Snow's unique circle of friends.* Toronto: Inclusion Press.

Perske, R. (1988). *Circles of friends: People with disabilities and their friends enrich the lives of one another.* Nashville, TN: Abingdon Press.

Piliavin, J. & Charng, H. (1990). Altruism: A review of recent theory and research. *Annual Review of Sociology, 16*: 27-65.

Pilisuk, M. & Parks, S. (1986). *The healing web: Social networks and human survival.* Hanover, NH: University Press of New England.

Sarason, S. (1988). *The Making of an American psychologist: An autobiography.* San Francisco: Jossey Bass.

Sarason, S., Carrol, C., Maton, K., Choen, S., & Lorentz, E. (1977). *Human services and resource networks.* San Francisco: Jossey Bass.

Schaefer, N. (1982). *Does she know she's there?* (updated edition). Toronto: Fitzhenry & Whiteside.

Shkilnyk, A. (1985). *A poison stronger than love: The destruction of an Ojibwa community.* New Haven: Yale University Press.

Snow, J. (1991). *Dreaming, speaking, and creating: What I know about community.* Toronto: Centre for Integrated Education and Community.

Snow, J. (1990, September) *The meaning of support as I experience it.* Presentation to Policy Institute on Natural Support sponsored by The Center on Human Policy at Syracuse University, Syracuse, NY.

Snow, J. (1989). Systems of support, A new vision. In S. Stainback, W. Stainback, & M. Forest (Eds.), *Educating all students in the mainstream of regular education.* Baltimore: Paul Brookes.

Snow, J. & Forest, M. (1988). *Support circles: Building a vision.* Toronto: Centre for Integrated Education and Community.

de Tocqueville, A. (1990). *Democracy in America* (12th ed.) [P. Bradley, Trans.], New York: Vintage Classics. [Original work published in 1848].

Traustadottir, R. (1990, March), Women, disability, and caring. *TASH Newsletter*, pp. 6-7.

Ungerson, C. (1987). *Policy is personal: Sex, gender, and informal care.* London:Tavistock Publications.

Weiss, R. (1973). *Loneliness: The experience of emotional and social isolation*. Cambridge, MA: MIT Press.

Weiss, R. (1982). Loneliness: What we know about it and what we might do about it. In L. Peplow & S. Goldstein (Eds.), *Preventing the harmful consequences of severe and persistent loneliness*. Rockville, MD: NIMH.

Walker, A. (1986). Community care: Fact and fiction. In P. Wilmott, ed. *The debate about community*. PSI Discussion paper No. 13. London: Policy Studies Institute.

Walker, A. (1982). *Community Care*. Oxford:Basil Blackwell.

Willmott, P. (1987). *Friendship networks and social support*. PSI Research Report No. 666. London: Policy Studies Institute.

Willmott, P. (1986). *Social networks, informal care, and public policy*. PSI Research Report No. 655. London: Policy Studies Institute.

World Institute on Disability & Rutgers University Bureau of Economic Research (n.d.). *The Need for Personal Assistance*. Oakland, CA: World Institute on Disability.

PART II: ANNOTATED BIBLIOGRAPHY ON RELATED READINGS

by Bonnie Shoultz, Zana Marie Lutfiyya
and Susan O'Connor

Almost all people need to feel that they belong and have meaningful relationships with others. Unfortunately, much of the literature reflects a belief that communities and the people in them are unable and unwilling to welcome people with developmental disabilities into their midst. There are studies on loneliness and isolation, courses on the sociology of deviance, and workshops and books on ways of overcoming community resistance.

These materials reflect a more positive way of thinking. They look at accepting relationships and responsive communities, and examine some of the dynamics that underlie these phenomena. They propose changes, not just in "the community," but in ourselves. In what ways have we--service providers, professionals, advocates--created the barriers we talk about? How can we best promote and support caring relationships and community participation? These materials attempt to address these issues at several levels.

- -

TITLE: The social basis of community care

AUTHOR: Bulmer, M.

PUBLICATION INFORMATION: 1987

Allen & Unwin, Inc.
8 Winchester Place
Winchester, MA 01890

This book analyzes the relationship between ideas about community life and the impact of social policy, demonstrating that, at least in England, there is "a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services" (p. ix). Bulmer's analysis is very relevant to North American discussions about community integration of people with disabilities. The book focuses more on informal support or care than on services and service systems, but he looks at both and at the interface between the two types of care in the community. His analysis draws heavily on a variety of research studies conducted in neighborhoods, within groups of families, and in other aspects of community life and is a major contribution to the discussion about community integration.

This book is addressed to academics and policy makers.

- -

TITLE: It's about relationships

AUTHOR: Forest, M.

PUBLICATION INFORMATION: 1989

Frontier College Press
35 Jackes Avenue
Toronto, Ontario M4T 1E2
CANADA

This essay is also a chapter in L. Meyer, C. Peck and L. Brown, Critical issues in the lives of people with disabilities, (1990), Paul Brookes Publishing Company. It is a personal reflection by Marsha Forest on the many relationships that have enriched her life and the lives of her friends and family members. Interwoven with the personal stories are stories about integrating students with disabilities into regular schools. Always, Forest points out how much we all have to give each other, and how much we miss when people with perceived differences are excluded from schools, neighborhoods, and friendship circles.

- -

- -

TITLE: The Joshua Committee: An advocacy model

AUTHORS: Forest, M., & Snow, J.

PUBLICATION INFORMATION: 1983, Winter

The Journal of Leisurability, 10(1).

TITLE: Friends circle to save a life

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1988, January

TASH Newsletter, 14(1).

TITLE: Friends circle to save a life

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1988, March

Augustus: A Journal of Progressive Human Services, XI(3).

In these three articles, the authors document the life of Judith Snow, a Canadian woman who has extensive physical disabilities. Although well educated and employed at York University, Ms. Snow was forced to live in a nursing home in order to receive the physical assistance that she needed. Through the combined efforts of several of her friends, Snow was enabled to leave the nursing home and move into her own apartment.

Forest and Snow share the insider's view of this story while Perske brings us up-to-date with the events of the past five years.

- -

TITLE: Everyone here spoke sign language

AUTHOR: Groce, N. E.

PUBLICATION INFORMATION: 1985

Harvard University Press
79 Garden Street
Cambridge, MA 02138

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance that deaf and hearing individuals were all community members. Those who could hear learned sign language so that communication could occur. Groce takes us beyond the confines of medical or social definitions of deviancy and offers evidence that our pre-conceived stereotypes of what a disability may mean is really determined by the social construct we create as a society.

This well-researched book is a must, not only for people interested in the field of disabilities but for anyone trying to struggle with integration into community life. The book contains a simple thesis offering a profound message in a wide area of disciplines. It will add thought to issues that will remain unresolved and discussed for a long time to come.

- -

TITLE: Understanding social networks

AUTHOR: Lambert, M.

PUBLICATION INFORMATION: 1983

Sage Publications
275 South Beverly Drive
Beverly Hills, CA 90212

This book pursues the increasing popularity of the concept of social networks in the human services field by offering the reader an organized and concise view not only of what networks are, but how they can be organized around individuals, groups, communities and organizations as a means to empower individuals.

First, the idea of networking is placed within its rich historical context which helps in demonstrating its well established value. As well as defined networking, its usage as a means of self-help and mutual aid are addressed. A common theme is that networks, when developed, will form a common chain and the networker will become the linkage connecting people to each other rather than relying on only the social services workers or agencies.

An idea that was addressed in the book but needs closer consideration in general is that of establishing natural networks with and for people. The book is a good over-all guide for those interested in looking at services beyond the service system and in need of some tools for how to go about initiating such a process.

- -

TITLE: Creating responsive communities: Reflections on a process of social change

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1985

Ontario Association for
the Mentally Retarded (OAMR)
1376 Bayview Avenue
Toronto, Ontario M4G 3A3
CANADA

A clear and concise look into one province's struggle in attempting to create a responsive community, this study addresses the idea that, by themselves, more rights and services for people with disabilities and their families are not enough, and that physical presence alone does not mean inclusion. True involvement within the community, it concludes, means necessary supports to allow full participation and opportunities for friendships.

The report focuses not only on lessons related to the emerging vision and strategies this organization used in promoting a sense of community, but also on some of the problems they encountered. A strong family and community emphasis is clear throughout the book, as well as the strength of advocacy in creating such environments. Self-advocacy is mentioned, also, but to a lesser degree. While much of the book deals with the historical development of the province's approach, some interesting and currently relevant principles are set forth in a chapter on assistance to individuals and families.

- -

TITLE: Affectionate bonds: What we can learn by listening to friends

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1990

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

In this monograph, Zana Lutfiyya describes a qualitative study conducted with four pairs of friends in the Syracuse area. In each of these pairs, one person has a disability label and one does not. The author offers perspectives on friendship found in the literature, describes each of her informants and their friendships, explores the dimensions and characteristics of friendship, and relates the rights, responsibilities and obligations of friendship in her informants' eyes. She discusses how some friendships move toward greater intimacy while others stay the same or die away, and lays out some of the implications of her study for the human service world, for families, and for people thinking about their own friendships. This ground-breaking study should begin to focus our thinking on what really goes on in friendships, including those between people with and without disabilities.

- -

- -

TITLE: Regenerating community

AUTHOR: McKnight, J. L.

PUBLICATION INFORMATION: 1987

Social Policy, Winter, 54-58.

McKnight begins this article with a discussion about problems with two primary orientations of social policy: institutions and individuals. He argues that the institutionalized social service system does not effectively meet the needs of individuals. Rather, it is a "design established to create control of people." As an alternative, he proposes that we look at the community--a structure of associations based on consent--to meet the needs of people. The "community of associations" is characterized by features such as interdependence, creativity, citizenship, and including: capacity, collective effort, informality, stories, celebration, and tragedy. McKnight argues that institutionalized systems grow at the expense of communities, and that instead of continuing to strengthen service systems we should work to strengthen communities. He concludes, "There is a mistaken notion that our society has a problem in terms of effective human services. Our essential problem is weak communities."

This short article will be of interest to people in the human services field--particularly those who are frustrated or dissatisfied with the social service system and its ability to meet people's needs. The challenge presented to human service workers, based on this article, is to see their role as one of helping people establish community connections and associations rather than more social service ones.

- -

TITLE: What are we learning about bridge-building?

AUTHOR: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

This monograph opens with the key premise of "bridge-building." "Real integration, the development of genuine networks of support, requires very focused and assertive effort(s) on behalf of facilitators who initiate, support and maintain new relationships. We call these facilitators bridge-builders because they build bridges and guide people into new relationships, new places, and new opportunities in life" (p. 1).

As the sub-title of the monograph suggests, it is a summary of a dialogue between people who are trying to build community for and with people with disabilities by working as bridge-builders. Most of the monograph presents the reflections of five participants at a day-long discussion on bridge-building in 1988. As this publication appears to be a faithful rendering of people's words, with little attempt at a full written explication of the concepts and terms that form the new language of bridge-building, it may be unsatisfying for someone who is completely new to the idea. However, it does contrast the different perspectives held by proponents of traditional human services with that of bridge-building, and would be of interest to those readers already acquainted with this concept.

- -

TITLE: What are we learning about circles of support?

AUTHOR: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

The authors offer the experiences of several "circles of support" now in existence in Connecticut. Inspired by the efforts of the Joshua Committee over the past decade, the authors helped found circles of support around several people with disabilities. "A circle of support is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (p. 3). The monograph gives practical information on the process of starting and maintaining a support circle, with several actual examples. Circles of support serves well as both an introduction to the concept and as a useful resource for people already familiar with the issue.

Acknowledging the current fascination with "personal futures planning," the authors provide an important comparison of support circles with person-centered and traditional methods of service planning. And they wisely caution that the process outlined in the monograph is not meant as a model for replication of other support circles. Rather, "the spirit of a circle...is more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people" (p. 1).

- -

TITLE: The gift of hospitality: Opening the doors of community life to people with disabilities

AUTHOR: O'Connell, M.

PUBLICATION INFORMATION: 1988

The Community Life Project
Center for Urban Affairs and Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208
(312) 491-3395

This monograph is part of the growing literature which critiques the human service system even when it is based in the community. It describes the efforts of people with a variety of disabilities to take their place within the community and by others to accept them. O'Connell asserts that community-based services can isolate people with disabilities from community life. Surrounded by paid staff, many clients in the human service system are cut off from the opportunities to meet and develop relationships with typical people.

By sharing the experiences of individuals with disabilities who have been welcomed into the hearts and lives of others, O'Connell introduces a practical definition of hospitality. She suggests that hospitality is "...the fundamental sense that you have to appeal to in asking other people to get involved in this work of welcoming isolated people back into the community." For the author, achieving the fullest possible integration of individuals with disabilities into society involves acts of welcome and hospitality by those who are already members.

This monograph would be useful reading for those interested in the meanings of "community integration" for people with disabilities.

- -

TITLE: Circles of friends

AUTHOR: Perske, R./Illustrated by Perske, M.

PUBLICATION INFORMATION: 1988

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

Circles of friends presents several stories of friendship between people with disabilities and those who are not disabled. After conducting interviews across Canada and the United States, the Perskes provide readers with several vignettes of friendships. They refer to these relationships as "living documents," proof that people "...once thought too limited or strange for life in ordinary neighborhood" enjoy a variety of friendships. The story and illustrations are alternately powerful, humorous, touching and life-affirming. This book is an upbeat account of the possibilities of friendship and is meant for a wide audience, both within and outside the field of mental retardation.

- -

- -

TITLE: New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better

AUTHOR: Perske, R./Illustrated by Perske, M.

PUBLICATION INFORMATION: 1980

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

Written by well-known author and leader in the field of developmental disabilities, Robert Perske, New life in the neighborhood presents a compelling case for the integration of people with developmental disabilities into typical neighborhoods and communities. The book provides a clear and straightforward explanation of normalization, debunks the myths surrounding people with mental retardation, explains why both typical and disabled people benefit from community integration, and addresses commonplace fears such as the impact of small community residences on property values. Sensitively and clearly written, this book is directed toward a popular audience, including civic leaders, prospective neighbors of the community residences, volunteers, and other non-professionals. This is a key source for anyone involved in developing integrated community living arrangements.

- -

TITLE: Social integration and friendship

AUTHOR: Strully, J. L., & Bartholomew-Lorimar, K.

PUBLICATION INFORMATION: 1988

In S. M. Pueschel (Ed.), The young person with Down Syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

In the first part of this chapter, Strully and Bartholomew-Lorimar neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely-given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

. . . .

TITLE: Friendship and our children

AUTHOR: Strully, J., & Strully, C.

PUBLICATION INFORMATION: 1985, Winter

Journal of The Association for Persons with Severe Handicaps, 10(4), 224-227.

The Strullys describe the friendship between one of their daughters, Shawntell, and one of her schoolmates, Tanya. They conclude that it is primarily through enjoying a number of close relationships and/or friendships with typical people that their daughter will be guaranteed a place in her community.

. . . .

TITLE: On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance

AUTHORS: Taylor, S. J., & Bogdan, R.

PUBLICATION INFORMATION: 1989

Disability, Handicap & Society, 4(1), 21-36.

This article outlines the "sociology of acceptance" as a theoretical framework for understanding some relationships between people with mental retardation and typical people. As a point of departure, the authors review sociocultural perspectives on deviance and explore their contribution to the study of mental retardation. Based on qualitative research at community programs for people with severe disabilities, the authors next examine the nature of accepting relationships and describe four sentiments expressed by typical people which account for their relationships with people with mental retardation: family; religious commitment; humanitarian sentiments; and feelings of friendship. The article concludes with a brief discussion of the implications of a sociology of acceptance for the field of mental retardation.

. . . .

TITLE: Ties and connections: An ordinary community life for people with learning difficulties

AUTHOR: Tyne, A. (Ed.)

PUBLICATION INFORMATION: 1988

King's Fund Centre
126 Albert Street
London, England NW1 7NF

This monograph is worth sending to England for. It attempts one of the more comprehensive discussions of interpersonal relationships in the lives of people with developmental disabilities (who are referred to in the publication as having "learning difficulties"). The monograph begins with descriptions of some of the types of relationships that people have and/or desire more of. These include friendship, acquaintances, organizational membership, being part of a family and a neighborhood. Some basic, common-sense strategies that families, disabled individuals, service workers and "typical citizens" might undertake in order to help maintain and increase the existing relationships in a person's life are outlined. The third and last chapter is a cautionary one that explores some of the difficulties faced by people with handicaps in developing a wide range of personal relationships.

TITLE: The new genocide of handicapped and afflicted people

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1987

Division of Special Education and Rehabilitation
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2180
(Copyright of W. Wolfensberger)

In this monograph, Wolfensberger attempts to describe the dangerous and life-threatening position that people with disabilities are currently placed in, largely because of their devalued status. The first sections of the monograph describe the "...negative experiences that befall devalued people," and would be appropriate reading for people interested in the process of turning people into clients.

TITLE: Citizen Advocacy and protective services for the impaired and handicapped

AUTHOR: Wolfensberger, W., & Zauha, H. (Eds.)

PUBLICATION INFORMATION: 1973

Toronto: National Institute on Mental Retardation.

TITLE: CAPE: Standards for Citizen Advocacy program evaluation

AUTHOR: O'Brien, J., & Wolfensberger, W.

PUBLICATION INFORMATION: 1980

Toronto: The Canadian Association for the Mentally Retarded.

TITLE: Learning from Citizen Advocacy programs

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1987

Atlanta: Georgia Advocacy Office.

As a concept put into practice, Citizen Advocacy (C.A.) is twenty-two years old. Formulated by Dr. Wolf Wolfensberger, it was part of a larger schema that delineated advocacy and protective services needed by people with mental retardation. These services were designed to provide the necessary protection for handicapped individuals who were unable to represent themselves and had no family or friends to safeguard their interests. Citizen Advocacy was an attempt to respond to the parents' question, "What will happen to my disabled son or daughter when I'm gone?" Wolfensberger defined Citizen Advocacy as "...a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention" (Wolfensberger & Zauha, 1973).

CAPE (O'Brien & Wolfensberger, 1980) is an evaluation tool designed to compare the practices found in a Citizen Advocacy program to the standards set by the definition and principles of Citizen Advocacy. CAPE is made up of 36 ratings which examine the efforts of the staff and board to recruit and introduce people who require protection, practical assistance, and/or friendship (proteges, partners) to capable citizens who attempt to address those needs (advocates).

O'Brien's manual (1987) provides an expanded definition and rearticulates the principles of Citizen Advocacy. This manual reflects the experiences of people in the United States, Canada, England, and Australia trying to put Wolfensberger's theory into practice. Learning from Citizen Advocacy programs is a collection of questions, activities, and resources about Citizen Advocacy. While external evaluation teams may use the manual (O'Brien suggests the possibility of doing so in conjunction with the CAPE tool), boards and staff of Citizen Advocacy offices may also use it to review their own work.

Despite the different purposes of these publications, all of the authors assume that at least some typical citizens will choose to become involved in a personal, one-to-one relationship with someone who is devalued by the society at large. Those interested in the concept of Citizen Advocacy are encouraged to read all three of these publications.

- -